Clinical Practice Guidelines for Quality Palliative Care

National Consensus Project
FOR QUALITY PALLIATIVE CARE

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Clinical Practice Guidelines for Quality Palliative Care

Palliative care programs are growing in response to patient need. They provide assessment and treatment of pain and other symptoms; help with patient-centered communication and decision-making; and coordination of care across settings and through serious illness. These Guidelines were developed through consensus of *five major United States palliative* care organizations and describe the core precepts and structures of clinical palliative care programs.

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Foreword

Palliative care and hospice programs have grown rapidly in recent years in response both to growth in the population living with chronic, debilitating and life-threatening illness and to clinician interest in effective approaches to the care of such patients. (1, 2) Palliative care is medical care provided by an interdisciplinary team, including the professions of medicine, nursing, social work, chaplaincy, counseling, nursing assistants and other health care professions, focused on the relief of suffering and support for the best possible quality of life for patients facing serious life-threatening illness, and their families. It aims to identify and address the physical, psychological, spiritual and practical burdens of illness. (2) This report will provide background on the clinical and educational imperatives that are driving the growth of palliative care and hospice services, review the outcomes of palliative care, describe its clinical components and the range of service models available, and present a professional consensus on the clinical guidelines for quality palliative care services.

The initiative to create a consensus on clinical practice guidelines for quality palliative care in the United States has its roots in the recommendations of three Institute of Medicine (IOM) reports, *Approaching Death, When Children Die,* and *Crossing the Quality Chasm*, as well as the American Association of Colleges of Nursing (AACN) report, *Peaceful Death*, and a recent monograph by the National Hospice Work Group (NHWG) and the Hastings Center, in association with the National Hospice and Palliative Care Organization (NHPCO), entitled *Access to Hospice Care: Expanding Boundaries, Overcoming Barriers.* (3, 4) All five reports call for substantive changes to improve access to palliative care across the life span, in all health care settings, during all stages of debilitating chronic or life-threatening illness or injury. These changes include enhancements in the quality of care, restructuring of health care system regulations on service, education of health care professionals and research to support evidence-based palliative care practice.

Broadening medical care to integrate palliative and life-prolonging interventions is a major challenge for health care in the United States. Because palliation is a critical dimension of health care, all patients should have access to primary health care practitioners who are skilled and knowledgeable about basic palliative therapies. All physicians need to know when the services of interdisciplinary specialist-level palliative care clinicians are indicated and how to access them. When a patient moves into the late stages of a life-threatening or debilitating condition, the relative

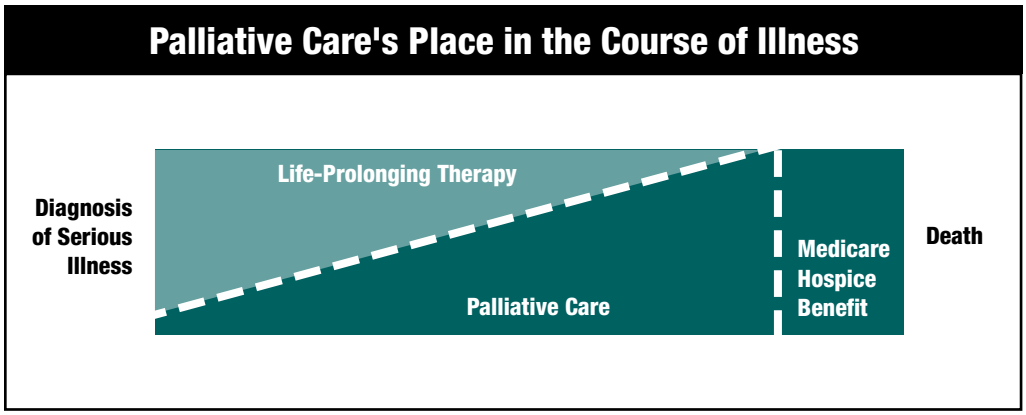
Note: Reference numbers in parentheses refer to the grouped references on pages 43 to 55. For complete citations, go to the bibliography at *www.nationalconsensusproject.org/guidelines.*

need for palliative care increases, and access to hospice programs must be enhanced to assure comprehensive and high-intensity palliative care during this stage of illness and during family bereavement. Such an approach should provide all patients with an integrated approach to treatment that looks to quality of life as well as quality of care throughout their experience with the health care system. Similarly, the palliative care needs of patients and families across the continuum should be met by a genuine and collaborative partnership between palliative care providers and hospice programs. Close coordination and partnerships between palliative care and hospice programs are critical to achieving continuity of palliative care throughout the full course of an illness and across the continuum of care settings.

The effort to integrate palliative care into all health care for debilitating and life-threatening illnesses should help to ensure that:

1. Pain and symptom control, psychosocial distress, spiritual issues and practical needs are addressed with patient and family throughout the continuum of care.
2. Patients and families obtain the information they need in an ongoing and understandable manner, in order to grasp their condition and treatment options. Their values and goals are elicited over time; the benefits and burdens of treatment are regularly reassessed; and the decision-making process about the care plan is sensitive to changes in the patient's condition.
3. Genuine coordination of care across settings is ensured through regular and high-quality communication between providers at times of transition or changing needs, and through effective continuity of care that utilizes the techniques of case management.
4. Both patient and family are prepared for the dying process and for death, when it is anticipated. Hospice options are explored, opportunities for personal growth are enhanced and bereavement support is available for the family.

The purpose of the National Consensus Project for Quality Palliative Care is to establish Clinical Practice Guidelines that promote care of consistent and high quality and that guide the development and structure of new and existing palliative care services. These guidelines are applicable to specialist-level palliative care delivered in a range of treatment settings, as well as to the work of providers in primary treatment settings where palliative approaches to care are integrated into daily clinical practice.



Definition of Palliative Care (5)

The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision-making and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care. (6)

Palliative care is operationalized through effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care according to patient/family needs, values, beliefs and culture(s). Evaluation and treatment should be comprehensive and patient-centered, with a focus on the central role of the family unit in decision-making. Palliative care affirms life by supporting the patient and family's goals for the future, including their hopes for cure or life-prolongation, as well as their hopes for peace and dignity throughout the course of illness, the dying process and death. Palliative care aims to guide and assist the patient and family in making decisions that enable them to work toward their goals during whatever time they have remaining. Comprehensive palliative care services often require the expertise of various providers in order to adequately assess and treat the complex needs of seriously ill patients and their families. Members of a palliative care team may include professionals from medicine, nursing, social work, chaplaincy, nutrition, rehabilitation, pharmacy and other professional disciplines. Leadership, collaboration, coordination and communication are key elements for effective integration of these disciplines and services.

Background

The hospice and pain management movements have demonstrated the efficacy of the patient-centered model of interdisciplinary team care and provided the impetus to formalize and promote a broader application of palliative care in the United States. In recent years, palliative care services outside hospice have increased rapidly in response to the growth in the population living with debilitating and life-limiting illnesses. The increase in demand for these services reflects the need to integrate and extend the well-established philosophy and practice of hospice care in this country to all stages of illness and to every care setting, including attention to symptom distress, patient and family support, and care coordination across settings. While there are aspects of contemporary palliative care that require specialized training for expert levels of knowledge and skill, the need for attention to palliative care issues is pervasive in the health care system. Palliative care, as an emerging health care specialty, is an important part of the response to these needs, serving both as a resource and a model for improved care throughout the trajectory of serious and life-threatening illness.

Patient Populations Served (7)

For the purposes of this document, the term *life-threatening or debilitating illness* is assumed to encompass the population of patients of all ages and a broad range of diagnostic categories, who are living with a persistent or recurring condition that adversely affects their daily functioning or will predictably reduce life expectancy.

Based on this definition, the patient population referred to includes:

- Children and adults with congenital injuries or conditions leading to dependence on life-sustaining treatments and/or long-term care by others for support of the activities of daily living.
- Persons of any age with acute, serious and life-threatening illnesses (such as severe trauma, leukemia or acute stroke), where cure or reversibility is a realistic goal, but the conditions themselves and their treatments pose significant burdens.
- Persons living with progressive chronic conditions (such as peripheral vascular disease, malignancies, chronic renal or liver failure, stroke with significant functional impairment, advanced heart or lung disease, frailty, neurodegenerative disorders and dementia).
- Persons living with chronic and life-limiting injuries from accidents or other forms of trauma.
- Seriously and terminally ill patients (such as persons living with end-stage dementia, terminal cancer or severe disabling stroke), who are unlikely to recover or stabilize, and for whom intensive palliative care is the predominant focus and goal of care for the time remaining.

Specialty-Level Palliative Care and Palliative Care in Primary Treatment Settings

Palliative care is both a general approach to patient care that should be routinely integrated with disease-modifying therapies and a growing practice specialty for appropriately trained physicians, nurses, social workers, chaplains and others whose expertise is required to optimize quality of life for those with life-threatening or debilitating chronic illness. Primary practitioners, in the routine course of providing health care, are expected to provide basic elements of palliative care (e.g., pain and symptom assessment and management, advance care planning). In other cases, complexity may determine that the patient or their family requires the services of palliative care specialists. Specialist palliative care providers are professionals whose work is largely or entirely involved with palliative care and who have received appropriate training and credentialing in the field. It is an expectation, fostered by these clinical guidelines, that palliative care services delivered by all health care professionals within the scope of their disciplines and care settings will rise to the level of "best practices" in order to meet the needs of their patients. The specialty of palliative care (programs and professionals committed largely or entirely to the delivery of palliative care), like other medical specialties, requires defined areas of expertise, skill and self-regulation. In health care settings without direct access to palliative care specialty services, resources should be sought through, for example, telemedicine or other forms of remote consultation.

The goal of these clinical guidelines is not to substitute one set of services (palliative) for another set of services (curative or disease-modifying), but rather to create an environment in which the needs of the patient, based on a comprehensive assessment, are fully considered. Only then can a reasonable determination be made of what mix of services is required to meet the physical, psychological, social, practical and spiritual needs of patients and their families. Good health care requires continual reappraisal of the benefits and burdens of therapies, and a proactive engagement with the philosophy of palliative care supports this fundamental tenet of the practice of medicine.

The World Health Organization defines palliative care as (5)

"An approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention, assessment, and treatment of pain and other physical, psychosocial, and spiritual problems.

Palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a part of the life cycle;
- Intends neither to hasten nor postpone death;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement, including the needs of children;
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- Will enhance the quality of life, and may also positively influence the course of a patient's illness."

Core Elements of Palliative Care

The World Health Organization (WHO) definition of palliative care provides a foundation and context for palliative care in all settings. The National Consensus Project agreed on the following key elements of palliative care:

- **Patient population:** The population served includes patients of all ages experiencing a debilitating chronic or life-threatening illness, condition or injury. (7)
- **Patient- and family-centered care:** The uniqueness of each patient and family is respected, and the patient and family constitute the unit of care. The family is defined by the patient or, in the case of minors or those without decision-making capacity, by their surrogates. In this context, family members may be related or unrelated to the patient; they are individuals who provide support and with

whom the patient has a significant relationship. The care plan is determined by the goals and preferences of the patient and family, (8) with support and guidance in decision-making from the health care team. (9)

- **Timing of palliative care:** Palliative care ideally begins at the time of diagnosis of a life-threatening or debilitating condition and continues through cure, or until death, and into the family's bereavement period. (2)
- **Comprehensive care:** Palliative care employs multidimensional assessment to identify and relieve suffering through the prevention or alleviation of physical, psychological, social and spiritual distress. (10) Care providers should regularly assist patients and their families to understand changes in condition and the implications of these changes as they relate to ongoing and future care and goals of treatment. Palliative care requires the regular and formal clinical process of patient-appropriate assessment, diagnosis, planning, interventions, monitoring and follow-up.
- **Interdisciplinary team:** Palliative care presupposes indications for, and provision of, interdisciplinary team evaluation and treatment in selected cases. (11) The palliative care team must be skilled in care of the patient population to be served. Palliative care teams may be expanded to include a range of professionals, based on the services needed. They include a core group of professionals from medicine, nursing and social work, and may include some combination of volunteer coordinators, bereavement coordinators, chaplains, psychologists, pharmacists, nursing assistants and home attendants, dietitians, physical-, occupational-, art-, play-, music-, and child-life-therapists, case managers and trained volunteers.
- **Attention to relief of suffering:** The primary goal of palliative care is to prevent and relieve the many and various burdens imposed by diseases and their treatments, and consequent suffering, including pain and other symptom distress. (12)
- **Communication skills:** Effective communication skills are requisite in palliative care. These include developmentally appropriate and effective sharing of information, active listening, determination of goals and preferences, assistance with medical decision-making, and effective communication with all individuals involved in the care of patients and their families. (13)
- **Skill in care of the dying and the bereaved:** Palliative care specialist teams must be knowledgeable about prognostication, signs and symptoms of imminent death, and the associated care and support needs of patients and their families before and after the death, including age-specific physical and psychological syndromes, opportunities for growth, normal and aberrant grief, and bereavement processes. (14)
- **Continuity of care across settings:** Palliative care is integral to all health care delivery system settings (hospital, emergency department, nursing home, home care, assisted living facilities, outpatient and nontraditional environments such as schools). The palliative care team collaborates with professional and informal caregivers in each of these settings, in order to ensure coordination, communication and continuity of palliative care across institutional and home care settings. Prevention of crises and unnecessary transfers are important outcomes of palliative care. (15)

- **Equitable access:** Palliative care teams should work toward equitable access to palliative care across all ages and patient populations, all diagnostic categories, all health care settings including rural communities, and regardless of race, ethnicity, sexual preference or ability to pay. (16)
- **Quality improvement:** Palliative care services should be committed to the pursuit of excellence and high quality of care. Determination of quality requires regular and systematic evaluation of the processes of care and measurement of outcomes data using validated instruments. (17) These aims are built around the core need for palliative care to incorporate attention at all times to safety and the systems of care that reduce error, and to be:
  - Timely—delivered to the right patient at the right time.
  - Patient-centered—based on the goals and preferences of the patient and the family.
  - Beneficial and/or effective—demonstrably influencing important patient outcomes or processes of care linked to desirable outcomes.
  - Accessible and equitable—available to all who are in need and who could benefit.
  - Knowledge- and evidence-based.
  - Efficient and designed to meet the actual needs of the patient and not wasteful of resources.

Models of Palliative Care Delivery

Palliative care is appropriate for all patients from the time of diagnosis with a life-threatening or debilitating condition, and service delivery should be structured accordingly. Palliative care services are most effective when integrated into specific care settings (e.g., hospital, nursing home, assisted living, home care, etc.). This requires training in the fundamentals of palliative care for practitioners in a range of primary treatment settings, as well as establishing referral patterns and access to credentialed palliative care specialists and formal palliative care teams.

Efforts to introduce and sustain palliative care delivery must be tailored to the needs of the patient population, providers, institution, specific care setting and local community. Palliative care services must organize and maintain an interdisciplinary team that can provide sufficient services including support for the family, continuity of care, optimal use of institutional and community resources, and close collaboration with other professionals involved with the care of the patient. Models of adult palliative care delivery may not be well suited to the needs of children. Where possible, pediatric palliative care should be delivered by professionals with skill and training in the care of children across a range of care settings, developmental stages and diagnostic categories. (18)

The established and proven model of palliative care at the end of life is hospice care. This form of care has been normalized in the United States through the provision of a Medicare Part A entitlement, the Medicare Hospice Benefit. (See Appendix 1 for a discussion of hospice care in the United States.) For individuals whose condition

warrants the use of similar comprehensive services at an earlier period in life, there is a broad array of emerging palliative care programs situated in acute hospital, hospice, home care, nursing home and community settings. Common organizational delivery models for palliative care programs inclusive of hospice programs include: (19)

- Consultation service team (usually in a hospital, office practice setting, nursing home or home setting), consisting of physician, nurse and/or social work evaluations.
- Dedicated inpatient unit (acute and rehabilitation hospital, nursing home) or combined with freestanding inpatient hospice.
- Combined consultative service team and inpatient unit (hospital and nursing home).
- Combined hospice program and palliative care program (hospital, nursing home and some freestanding hospice inpatient facilities).
- Hospital- or private-practice-based outpatient palliative care practice or clinic.
- Hospice-based palliative care at home.
- Hospice-based consultation in outpatient settings.

The Need for Further Expansion of Palliative Care Services

Repeated surveys of patient preferences and current care outcomes strongly support the need for expanded access to palliative care services. There continues to be a high prevalence of undertreated pain and other distressing symptoms in hospital, office practice, home care and nursing home settings among seriously ill patients of all ages and in all stages of illness. In addition, multiple studies document poor communication about the goals of care among health care practitioners, patients and families. (13) Despite the fact that more than 90 percent of Americans say they would rather be cared for at home, more than three-quarters of all deaths in the U.S. occur in hospitals (about 50 percent) or nursing homes (about 25 percent). (20) Recent research demonstrates high family caregiver burden, as well as increased morbidity and mortality for the family members of patients with chronic and life-threatening illness. (21)

Infant and child mortality rates associated with once-fatal illnesses and conditions are decreasing and more children now survive with severe or life-threatening disabilities. Palliative care for children is influenced by developmental considerations affecting diagnostic, treatment and communication approaches, as well as options for care. Physical, emotional and spiritual suffering in both pediatric patients and their families is clearly documented in recent studies. Serious illness in children is associated with high levels of uncertainty about prognosis and optimum management strategies, as well as great difficulty in accepting the possibility of death. Advance directives are not recognized for children, although the role of children in shared medical decision-making about their own care is critical. In contrast to older adults, nearly all of whom have Medicare coverage, about 15 percent of American children have no health insurance at all, and those with coverage have widely variable access to palliative care services. Nearly 85 percent of pediatric deaths currently occur in hospitals where pediatric palliative care services are largely unavailable or inadequate. (18)

Further impetus for expansion of palliative care services is the strong correlation between patient/family care preferences and the services provided by palliative care specialists. Studies show that patients' top priorities are to be free of physical and psychological distress; to have some control over decisions about their health care; to avoid death-prolonging treatments; and to improve relationships with and reduce burden on their families. (8) The evidence base of the hospice experience for patients/families during the last few months of a terminal illness, as well as more recent palliative care outcome studies, demonstrate the ability of palliative care to help patients achieve these goals throughout the trajectory of a progressive or life-threatening illness. (22) Other studies have demonstrated financial benefits associated with palliative care programs, including reduction in hospital length of stay, costs and utilization, (23) and increased numbers of referrals to and length of stay in hospice programs. (24)

The need for palliative care in the United States can be met through ongoing health professional education in palliative care principles and practice; increasing access to palliative care specialists in hospital, nursing home and home care settings; promoting timely access to hospice services to all eligible patients; creatively integrating hospice and palliative care programs across treatment settings; and defining appropriate accountability and performance measures for palliative care services.

The Urban Institute reports,

"The nation is about to experience a great demographic shock. Between 2010 and 2030 the over-65 population will rise over 70 percent, while under current law the population paying payroll taxes will rise less than 4 percent."(25) This demographic change, when aligned with progressively higher health care costs, diminishing labor and financial resources, insecurity of federal entitlements and longer life expectancies creates a dramatic projection of future health care needs. Further, the number of children living with life-limiting conditions with significant disability and morbidity continues to increase. (18) These factors help to illustrate the need for more effective application and coordination of chronic disease management services, including the integration of palliative care, in order to more effectively meet the needs of the growing number of persons living with life-threatening and debilitating illnesses.

Palliative Care Across the Continuum

The growing need for and interest in palliative care underscores the importance of practice guidelines aimed at promoting palliative care clinical services of a high and consistent quality across all relevant care settings in the United States. Most people receive health care in multiple clinical settings: physicians' offices, hospitals, school-based clinics, nursing homes, emergency facilities and at home. It is well established that communication among these various care settings is extremely difficult, resulting in discontinuities of care. Continuity of care is especially important for patients and families facing life-threatening illness or injury. Toward this end, a core value of palliative care is the promotion and facilitation of continuity of care to avoid needless suffering and errors, eliminate patient and family perceptions of abandonment, and ensure that choices and preferences are respected. (13, 15)

Almost all persons with serious illness spend at least some time in a hospital, usually on multiple occasions, in the course of the disease or condition. More than 50 percent of adult and 85 percent of pediatric deaths occur in hospitals. Similarly, almost half the population age 65 or older will spend some time in a nursing home prior to death, more than half of persons over age 85 die in a nursing home, and 43 percent of persons over age 65 reside in a long-term care facility at some time before they die. (26) Data from numerous studies demonstrate high degrees of symptom distress across all age groups in hospitalized and nursing home patients; high use of burdensome nonbeneficial technologies among the seriously ill; (27) caregiver burden on families; (21) and problems with communication between these patients, their families and their treating physicians about the goals of care and the medical decisions that should follow. (13)

In addition to serving as a principal location of care, hospitals are the primary training site for the nation's future health care professionals. As a result, hospitals have become a major locus of current efforts to improve access to palliative care. Providers must learn how to respond competently to the various forms of human suffering, know how to work with the medical system on behalf of patients and families, and to regard care of the dying, as well as the care of the chronically and seriously ill, as a core clinical responsibility. They must be taught and mentored at their point of entry into health care and in the environment—the hospital setting—where the majority of people will spend some time during a serious illness. Students of medicine and nursing are acculturated during their training to value what is taught and practiced by their seniors. Palliative care must be taught during clinical rotations in the hospital, in order for it to be viewed as an essential competency for a health professional.

Experiences in nonhospital community settings, including hospice, are also necessary to train future practitioners in both the primary and specialist-level skills required to ensure quality palliative care across all health care settings. As mandated by both the Liaison Council on Medical Education (undergraduate medical education) and the Accreditation Council on Graduate Medical Education (residency and fellowship training), this requires formal educational experiences both within and outside the hospital environment in order to fully understand the importance of continuity of care and the challenges of delivering it. Furthermore, the essential skills of learning to access and utilize community resources, and how to establish practice patterns that will promote palliative care in all settings, can only be gained through educational experiences in the range of settings where patients receive care. (28)

While the practice guidelines for palliative care clinical programs contained in this document are applicable in institutional settings for both pediatric and adult patient populations, focused efforts are required to improve access to quality palliative care in nursing homes, where perceived and actual regulatory barriers, limited resources and staff turnover often make the provision of expert palliative care services difficult. Additional education and training of nursing home professionals and all direct-care staff in the principles and practice of palliative care is a priority of long-term care professional organizations, and many facilities are developing palliative care capabilities on-site or through contractual relationships with palliative care clinicians. Promotion of contractual relationships between nursing homes and hospices is also a prevalent and growing model of palliative care delivery in the nursing home setting. Compared to nursing homes without hospice relationships, homes with hospice relationships show significant reductions in hospitalizations, hospital lengths of stay, restraint use, use of injection analgesics, and insertion of intravenous lines and feeding tubes, as well as a higher likelihood of detection and treatment of pain. (29) Consequently, a nursing home's ability to provide the types of palliative services identified in this document may be achieved through development of on-site capabilities in the delivery of quality palliative care; through seeking one or more contractual relationships with local hospices or palliative care experts; and, as some long-term care facilities have demonstrated, through development of palliative care consultation services in addition to hospice contracts. (30)

The Need for Consensus

Professional consensus on what constitutes high-quality palliative care is prerequisite to the effective delivery of such services across the continuum of care. This consensus process provides credible common ground to begin systematic improvements in palliative care delivery. In addition, the consensus process fosters the development of a broad-based and enduring palliative care constituency through the dissemination of these guidelines throughout the many sectors of the U.S. health care system.

Purpose of the Clinical Practice Guidelines for Quality Palliative Care

The mission of the National Consensus Project for Quality Palliative Care is to create a set of clinical practice guidelines to improve the quality of palliative care in the United States. Specifically, these Clinical Practice Guidelines for Quality Palliative Care aim to promote quality and reduce variation in new and existing programs, develop and encourage continuity of care across settings, and facilitate collaborative partnerships among palliative care programs, community hospices and a wide range of other health care delivery settings.

While the focus of this document is on the specialist component of palliative care (programs and professionals whose work is primarily focused on palliative care), most palliative care needs to be delivered in primary treatment settings in the course of routine care. This requires guidance for health care professionals who lack specialist training in palliative care. Thus, these guidelines are intended to serve as a comprehensive description of what constitutes a high-quality palliative care clinical service, as well as a resource for practitioners addressing the palliative care needs of patients and families in primary treatment settings.

In the United States, practice standards for palliative care during the last phase of life have developed over the last 20 years through hospice professional organizations and regulatory bodies. These standards and precepts, along with published palliative care service guidelines from Australia, New Zealand and Canada, served as the basis for the development of these clinical practice guidelines. (31)

The success of this project will be determined by the degree to which the Clinical Practice Guidelines for Quality Palliative Care are used to: 1) foster the integration of the principles, philosophy and practices of palliative care across care settings; 2) stimulate and guide the development and evaluation of new and existing services within and across care settings; 3) ensure that palliative care services deliver care of consistent and measurably high quality; 4) promote formal recognition of specialty status for certification initiatives in palliative care; and 5) support the expansion of efforts by hospices and other palliative care programs to coordinate care services across the continuum.

The purposes of these Clinical Practice Guidelines for Quality Palliative Care are to:

1. Facilitate the development and continuing improvement of clinical palliative care programs providing care to patients and families with life-threatening or debilitating illness.
2. Establish uniformly accepted definitions of the essential elements in palliative care that promote quality, consistency and reliability of these services.
3. Establish national goals for access to quality palliative care.
4. Foster performance measurement and quality improvement initiatives in palliative care services.
5. Foster continuity of palliative care across settings (home, residential care, hospital, hospice).

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NHPCO Standards: {ARE 3, 3.1-3.3, 3.5, 3.6, 8, 14, 14.1, 14.2; CCS 3.1-3.4, 6, 10, 10.1-10.3, 11, 11.1, 11.3, 13, 13.1, 13.2, 14, 14.1, 14.2; HIF CCS 3; HIF SIC 1,1.1-1.7, 5; HRCF SIC 1, 1.1-1.9, 2, 2.1-2.6, 3, 3.1, 5, 7, 7.1-7.4; HR 1, 1.3, 4, 4.1, 4.2, 4.4, 7.2; IDT 1.1, 4.1, 5.1; PI 1.1, 2, 2.1-2.3, 3.2, 4, 4.1, 4.3, 4.4, 5.2, 5.3, 6, 6.1,6.2}[1]

[1] References from sections of the National Hospice and Palliative Care Organization Standards of Practice for Hospice Programs (2002) are cited in brackets, using their abbreviations as follows:

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CC	Coordination and Continuity of Care	SIC	Safety and Infection Control
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HR	Human Resources	NF	Nursing Facility Hospice Care
IDT	Interdisciplinary Team	HRCF	Hospice Residential Care Facility
LG	Leadership and Governance		

Clinical Practice Guidelines for Quality Palliative Care

Baseline Assumptions

The following assumptions are fundamental to the development of the Clinical Practice Guidelines for Quality Palliative Care:

- **Goal guidelines:** These palliative care guidelines represent goals that palliative care services should strive to attain, as opposed to minimal or lowest acceptable practices.
- **Health care quality standards:** These palliative care guidelines assume that palliative care services will follow established practice standards and requirements for health care quality such as safety, effective leadership, medical record keeping and error reduction.
- **Codes of ethics:** These guidelines assume adherence to established professional and organizational codes of ethics.
- **Ongoing revision:** Palliative care guidelines will evolve as professional practice, the evidence base and the health care system change over time. These guidelines were written assuming an ongoing process of evidence-based evaluation and revision. (32)
- **Peer-defined guidelines:** These clinical practice guidelines were developed through a consensus process including a broad range of palliative care professionals; they are not linked to regulatory or reimbursement criteria and are not mandatory. However, they are written with the intent that they will be used as guidelines to promote the development of highest-quality clinical palliative care services across the health care continuum.
- **Specialty care:** When this document refers to specialty-level palliative care services it assumes provision of services by palliative care professionals within an interdisciplinary team whose work reflects substantial involvement in the care of patients with life-threatening or debilitating chronic illnesses, and their families. Palliative care qualifications are determined by organizations granting professional credentials and programmatic accreditation.
- **Continuing professional education:** These guidelines assume ongoing professional education for all palliative care professionals in the knowledge, attitudes and skills required to deliver quality palliative care across the domains established in this document.
- **Applicability of guidelines:** These guidelines should promote integration and application of the principles, philosophy and practices of palliative care across the continuum of care by both professional and certified caregivers in these settings.

Clinical Practice Guidelines for Quality Palliative Care

Excellence in specialist-level palliative care requires expertise in the clinical management of problems in multiple domains, supported by a programmatic infrastructure that furthers the goals of care and supports practitioners. Eight domains were identified as the framework for these guidelines: Structure and Processes; Physical Aspects of Care; Psychological and Psychiatric Aspects of Care; Social Aspects of Care; Spiritual, Religious and Existential Aspects of Care; Cultural Aspects of Care; Care of the Imminently Dying Patient; and Ethical and Legal Aspects of Care. These domains were drawn from the work of the previously established Australian, New Zealand, Canadian, Children's Hospice International, and NHPCO standards efforts. (31)

The guidelines rest on fundamental processes that cross all domains and encompass assessment, information sharing, decision-making, care planning and care delivery. Each domain is followed by specific clinical practice guidelines regarding professional behavior and service delivery. These are followed by justifications, supporting and clarifying statements, and suggested criteria for assessing whether or not the identified expectation has been met. References to the literature supporting these recommendations are included in the guidelines.

Domains of Quality Palliative Care

1. **Structure and Processes of Care**
2. **Physical Aspects of Care**
3. **Psychological and Psychiatric Aspects of Care**
4. **Social Aspects of Care**
5. **Spiritual, Religious and Existential Aspects of Care**
6. **Cultural Aspects of Care**
7. **Care of the Imminently Dying Patient**
8. **Ethical and Legal Aspects of Care**

Domain 1: Structure and Processes of Care

Guideline 1.1 The plan of care is based on a comprehensive interdisciplinary assessment of the patient and family. (10, 11)

Criteria:

- Assessment and its documentation are interdisciplinary and coordinated.
- Initial and subsequent assessments are carried out through patient and family interview, review of medical records, discussion with other providers, physical examination and assessment, and relevant laboratory and/or diagnostic tests or procedures. (33)
- Assessment includes documentation of disease status, including diagnoses and prognosis; comorbid medical and psychiatric disorders; physical and psychological symptoms; functional status; social, cultural, spiritual and advance care planning concerns and preferences, including appropriateness of referral to hospice. (34) Assessment of children must be conducted with consideration of age and stage of neurocognitive development. (35)
- Patient and family expectations, goals for care and for living, (8) understanding of the disease and prognosis, (13) as well as preferences for the type (8) and site of care (20, 26) are assessed and documented.
- The assessment is reviewed on a regular basis. (36)

Guideline 1.2 The care plan is based on the identified and expressed values, goals and needs of patient and family (8)**, and is developed with professional guidance and support for decision-making.** (9)

Criteria:

- The care plan is based upon an ongoing assessment, determined by goals set with patient and family, and with consideration of the changing benefit/burden assessment at critical decision points during the course of illness. (8)
- The care plan is developed through the input of patient, family, caregivers, involved health care providers, and the palliative care team with the additional input, when indicated, of other specialists (37) and caregivers, such as school professionals, clergy, friends, etc. (38)
- Care plan changes are based on the evolving needs and preferences of the patient and family over time, and recognize the complex, competing and shifting priorities in goals of care. (36)
- The interdisciplinary team coordinates and shares the information, provides support for decision-making, develops and carries out the care plan, and communicates the palliative care plan to patient and family, to all involved health professionals and to the responsible providers when patients transfer to different care settings. (13, 15)
- Treatment and care setting alternatives are clearly documented and communicated, and permit the patient and family to make informed choices. (8, 13)
- Treatment decisions are based on goals of care, assessment of risk and benefit, best evidence and patient/family preferences. Re-evaluation of treatment efficacy and patient-family preferences is documented. (36, 39)
- The evolving care plan must be clearly documented over time. (39)

Guideline 1.3 An interdisciplinary team provides services to the patient and family, consistent with the care plan.

Criteria:

- Specialist-level palliative care is delivered by an interdisciplinary team. (11)
- The team includes palliative care professionals with the appropriate patient population-specific education, credentialing and experience, and ability to meet the physical, psychological, social and spiritual needs of both patient and family. (14) Of particular importance is hiring physicians, nurses and social workers appropriately trained and ultimately certified in hospice and palliative care.
- The interdisciplinary palliative care team involved in the care of children, either as patients or as the children of adult patients, has expertise in the delivery of services for such children. (35)
- The patient and family have access to palliative care expertise and staff 24 hours per day, seven days per week. (40)
- Respite services are available for the families and caregivers of children or adults with life-threatening illnesses. (41)
- The interdisciplinary team communicates regularly (at least weekly, more often as required by the clinical situation) to plan, review and evaluate the care plan, with input from both patient and family. (42)
- The team meets regularly to discuss provision of quality care, including staffing, policies and clinical practices. (42)
- Team leadership has appropriate training, qualifications and experience. (43)
- Policies for prioritizing and responding to referrals in a timely manner are documented. (44)

Guideline 1.4 The interdisciplinary team may include appropriately trained and supervised volunteers. (45)

Criteria:

- If volunteers participate, policies and procedures are in place to ensure the necessary education of volunteers, and to guide recruitment, screening, training, work practices, support, supervision and performance evaluation, and to clarify the responsibilities of the program to its volunteers.
- Volunteers are screened, educated, coordinated and supervised by an appropriately educated and experienced professional team member.

Guideline 1.5 Support for education and training is available to the interdisciplinary team.

Criteria:

- Educational resources and continuing professional education focused on the domains of palliative care contained in this document are regularly provided to staff, and participation is documented. (46)

Guideline 1.6 The palliative care program is committed to quality improvement in clinical and management practices. (17)

Criteria:

- The palliative care program must be committed to the pursuit of excellence and the highest quality of care and support for all patients and their families. Determining quality requires regular and systematic measurement, analysis, review, evaluation, goal setting, and revision of the processes and outcomes of care provided by the program.
- Quality care must incorporate attention at all times to:
  - Safety, and the systems of care that reduce error.
  - Timeliness, care delivered to the right patient at the right time.
  - Patient-centered care, based on the goals and preferences of the patient and the family.
  - Beneficial and/or effective care, demonstrably influencing important patient outcomes or processes of care linked to desirable outcomes.
  - Equity, care that is available to all in need and who could benefit.
  - Efficiency, care designed to meet the actual needs of the patient so that it does not waste resources.
- The palliative care program establishes quality improvement policies and procedures.
- Quality improvement activities are routine, regular, reported and are shown to influence clinical practice.
- The clinical practices of palliative care programs reflect the integration and dissemination of research and evidence of quality improvement.
- Quality improvement activities for clinical services are collaborative, interdisciplinary, and focused on meeting the identified needs of patients and their families.
- Patients, families, health professionals and the community may provide input for evaluation of the program.

Guideline 1.7 The palliative care program recognizes the emotional impact on the palliative care team of providing care to patients with life-threatening illnesses and their families. (47)

Criteria:

- Emotional support is available to staff and volunteers as appropriate.
- Policies guide the support of staff and volunteers, including regular meetings for review and discussion of the impact and processes of providing palliative care.

Guideline 1.8 Palliative care programs should have a relationship with one or more hospices and other community resources in order to ensure continuity of the highest-quality palliative care across the illness trajectory. (38)

Criteria:

- Palliative care programs must support and promote continuity of care across settings and throughout the trajectory of illness.
- As appropriate, patients and families are routinely informed about and offered referral to hospice and other community-based health care resources.
- Referring physicians and health care providers are routinely informed about the availability and benefits of hospice and other community resources for care for their patients and families as appropriate and indicated.
- Policies for formal written and verbal communication about all domains in the plan of care are established between the palliative care program, hospice programs, and other major community providers involved in the patients' care. Policies enable timely and effective sharing of information among teams while safeguarding privacy.
- Where possible, hospice and palliative care program staff routinely participate in each other's team meetings to promote regular professional communication, collaboration and an integrated plan of care on behalf of patients and families.
- Palliative and hospice care programs, as well as other major community providers, routinely seek opportunities to collaborate and work in partnership to promote increased access to quality palliative care across the continuum.

Guideline 1.9 The physical environment in which care is provided should meet the preferences, needs and circumstances of the patient and family to the extent possible.

Criteria:

- When feasible, care is provided in the setting preferred by the patient and their family. (19, 20)
- When care is provided away from the patient's home, the care setting addresses safety and, as appropriate and feasible, flexible or open visiting hours, space for families to visit, rest, eat or prepare meals, and meet with the palliative care team and other professionals, as well as privacy and other needs identified by the family. (48) The setting should address the unique care needs of children as patients, family members or visitors. (35)

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NHPCO Standards {ARE 1.1, 3.3, 3.4, 8; CC 1, 1.1-1.3, 1.5 2, 2.1, 2.3;CCS 1, 1.1-1.3, 2, 2.1, 2, 2.1-3.3, 8, 10, 11, 13, 14, 14.1, 14.2; HIF CCS 3; HIF SIC 1,1.1-1.7, 5; HR 1.1, 3.5, 3.6, 4, 4.1-4.5, 5, 5.1- 5.4, 6, 6.1-6.3, 7, 7.1, 7.2, 7.5, 9, 9.1, 9.2; HRCF SIC 1, 1.1-1.9, 2, 2.1-2.6, 3, 3.1, 5, 7, 7.1-7.4; IDT 3.1, 6, 6.3, 7.1, 11.1 12.1, 12.2, 12.4, 13.3, 15.5; LG 8.2, 12; MI 1.1, 1.2, 3.3}[1]

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HIF	Hospice Inpatient Facility
NF	Nursing Facility Hospice Care
HRCF	Hospice Residential Care Facility

Domain 2: Physical Aspects of Care

Guideline 2.1 Pain, other symptoms and side effects are managed based upon the best available evidence, which is skillfully and systematically applied. (32)

Criteria:

- The interdisciplinary team includes professionals with specialist-level skill in symptom control (11, 14).
- Regular, ongoing assessment of pain, nonpain symptoms (including but not limited to shortness of breath, nausea, fatigue and weakness, anorexia, insomnia, anxiety, depression, confusion and constipation), treatment side effects and functional capacities are documented. (49-79) Validated instruments, where available, should be used. (80) Symptom assessment in children and cognitively impaired patients should be performed with appropriate tools. (35)
- The outcome of pain and symptom management is the safe and timely reduction of pain and symptom levels, for as long as the symptom persists, to a level that is acceptable to the patient.
- Response to symptom distress is prompt and tracked, through documentation in the medical record. (39, 51)
- Barriers to effective pain management should be recognized and addressed, including inappropriate fears of the risks of side effects, addiction, respiratory depression and hastening of death in association with opioid analgesics. (49-51)
- A risk management plan should be implemented when controlled substances are prescribed for long-term symptom management.
- Patient understanding of disease and its consequences, symptoms, side effects of treatments, functional impairment and potentially useful treatments is assessed. The capacity of the patient to secure and accept needed care and to cope with the illness and its consequences is assessed. (13) (See Domain 3: Psychological and Domain 8: Ethics).
- Family understanding of the disease and its consequences, symptoms, side effects, functional impairment and treatments is assessed. The capacity of the family to secure and provide needed care and to cope with the illness and its consequences is assessed. (13, 21)
- Treatment of distressing symptoms and side effects incorporates pharmacological, nonpharmacological and complementary/supportive therapies. (78, 79) Approach to the relief of suffering is comprehensive, addressing physical, psychological, social and spiritual aspects. (10) (See especially Domain 3: Psychological and Domain 4: Social Support).
- Referrals to health care professionals with specialized skills in symptom management are made available when appropriate (e.g., radiation therapists, anesthesia pain management specialists, orthopedists, physical and occupational therapists, child life specialists). (37)
- Family is educated and supported to provide safe and appropriate comfort measures to the patient. Family is provided with backup resources for response to urgent needs. (See Domain 3: Psychological and Domain 4: Social Support).
- A process for quality improvement and review of physical and functional assessment and effectiveness of treatment is documented and leads to change in clinical practice. (17)

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NF	Nursing Facility Hospice Care
HRCF	Hospice Residential Care Facility

Domain 3: Psychological and Psychiatric Aspects of Care

Guideline 3.1 Psychological and psychiatric issues are assessed and managed based upon the best available evidence, which is skillfully and systematically applied. (32, 81)

Criteria:

- The interdisciplinary team includes professionals with patient-specific skill and training in the psychological consequences and psychiatric comorbidities of serious illness for both patient and family, (82) including depression, (55) anxiety, (53) delirium (54) and cognitive impairment. (68, 84) (See Domain 2: Physical Aspects of Care).
- Regular, ongoing assessment of psychological reactions (83) (including but not limited to stress, anticipatory grieving and coping strategies) and psychiatric conditions occurs and is documented. (36) Whenever possible, a validated and context-specific assessment tool should be used. (80, 84, 85)
- Psychological assessment includes patient understanding of disease, symptoms, side effects and their treatments, as well as assessment of caregiving needs, capacity and coping strategies. (13, 81, 83, 86)
- Psychological assessment includes family understanding of the illness and its consequences for the patient as well as the family; assessment of family caregiving capacities, needs and coping strategies. (13, 21, 81, 83, 84, 87)
- Family is educated and supported to provide safe and appropriate psychological support measures to the patient. (21, 87)
- Pharmacologic, nonpharmacologic and complementary therapies are employed in the treatment of psychological distress or psychiatric syndromes, as appropriate. (84) Treatment alternatives are clearly documented and communicated and permit the patient and family to make informed choices. (13)
- Response to symptom distress is prompt and tracked, through documentation in the medical record. Regular reevaluation of treatment efficacy and patient-family preferences is documented. (36)
- Referrals to health care professionals with specialized skills in age-appropriate psychological and psychiatric management are made available when appropriate (e.g., psychiatrists, psychologists and social workers). Identified psychiatric comorbidities in family or caregivers are referred for treatment. (37)
- Developmentally appropriate assessment and support is provided to pediatric patients, their siblings, and the children or grandchildren of adult patients. (35)
- Communication with children and cognitively impaired individuals occurs using verbal, nonverbal and/or symbolic means appropriate to developmental stage and cognitive capacity.

- Treatment decisions are based on goals of care, assessment of risk and benefit, best evidence and patient/family preferences. The goal is to address psychological needs, treat psychiatric disorders, promote adjustment, and support opportunities for emotional growth, healing, reframing, completion of unfinished business and support through the bereavement period. (83-87)
- A process for quality improvement and review of psychological and psychiatric assessment and effectiveness of treatment is documented and leads to change in clinical practice. (17)

Guideline 3.2 A grief and bereavement program is available to patients and families, based on the assessed need for services. (88)

Criteria:

- The interdisciplinary team includes professionals with patient-population-appropriate education and skill in the care of patients and families experiencing loss, grief and bereavement. (14, 89)
- Bereavement services are recognized as a core component of the palliative care program. (88, 90-93)
- Bereavement services and follow-up are made available to the family for at least 12 months, or as long as is needed, after the death of the patient. (93)
- Grief and bereavement risk assessment is routine, developmentally appropriate and ongoing for the patient and family throughout the illness trajectory, recognizing issues of loss and grief in living with a life-threatening illness. (92)
- Clinical assessment is used to identify people at risk of complicated grief and bereavement, and its association with depression and comorbid complications, particularly among the elderly. (88, 90, 92, 93)
- Information on loss and grief and the availability of bereavement support services, including those available through hospice and other community programs, is made routinely available to families before and after the death of the patient, as culturally appropriate and desired. (90)
- Support and grief interventions are provided in accordance with developmental, cultural and spiritual needs, expectations and preferences of the family, including attention to the needs of siblings of pediatric patients and children of adult patients. (91)
- Staff and volunteers who provide bereavement services receive ongoing education, supervision and support. (47, 94)
- Referrals to health care professionals with specialized skills are made when clinically indicated. (37)

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NOTE: An easy reference to the various sections of the NHPCO Standards of Practice for Hospice Programs (2000) is provided in brackets at the end of each domain.

NHPCO Standards {BCS 1, 2.1, 2.2, 2.3, 3.4; CCS 5.4; IDT 1, 1.1, 1.6, 3.3, 5.1, 6.3; PI 4, 4.1, 4.3, 4.4, 5.2, 6}[1]

[1] References from sections of the National Hospice and Palliative Care Organization Standards of Practice for Hospice Programs (2002) are cited in brackets, using their abbreviations as follows:

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PI	Performance Improvement and Outcomes Measurement
SIC	Safety and Infection Control
HIF	Hospice Inpatient Facility
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HRCF	Hospice Residential Care Facility

Domain 4: Social Aspects of Care

Guideline 4.1 Comprehensive interdisciplinary assessment identifies the social needs of patients and their families, and a care plan is developed in order to respond to these needs as effectively as possible. (95)

Criteria:

- The interdisciplinary team includes professionals with patient-population-specific skills in the assessment and management of social and practical needs during a life-threatening or chronic debilitating illness. (14)
- Practitioners skilled in the assessment and management of the developmental needs of children should be available for pediatric patients and the children of adult patients, as appropriate. (35)
- A comprehensive interdisciplinary social assessment is completed and documented, to include: family structure and geographic location; relationships; lines of communication; existing social and cultural networks; perceived social support; medical decision-making; work and school settings; finances; sexuality; intimacy; living arrangements; caregiver availability; access to transportation; access to prescription and over-the-counter medicines and nutritional products; access to needed equipment; community resources including school and work settings; and legal issues. (8, 9, 12, 13, 20, 21, 35, 36, 38, 96-100) (See Domain 6: Culture).
- Routine patient and family meetings (101) are conducted with members of the interdisciplinary team to assess understanding and address questions, provide information and help with decision-making, discuss goals of care and advance care planning, determine wishes, preferences, hopes and fears, provide emotional and social support and enhance communication.
- The social care plan is formulated from a comprehensive social and cultural assessment and reassessment, and reflects and documents values, goals and preferences as set by patient and family over time. (8, 20) Interventions are planned to minimize adverse impact of caregiving on the family and to promote caregiver and family goals and well-being. (21)
- Referrals to appropriate services are made that meet identified social needs and promote access to care, help in the home, school or work, transportation, rehabilitation, medications, counseling, community resources and equipment. (38)

Selected References for Domain 4

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NOTE: An easy reference to the various sections of the NHPCO Standards of Practice for Hospice Programs (2000) is provided in brackets at the end of each domain.

NHPCO Standards {CCS 6, 6.1, 6.2, 6.3, 7, 7.1, 7.2, 9, 9.1, 9.2, 9.3, 10, 10.1, 10.2, 10.3, 11, 11.3, 12, 12.1, 12.2, 12.3, 12.4, 13, 13.1, 13.2, 14, 14.1, 14.2; IDT 1.1, 5.1, 6, 6.3, 11, 11.1, 11.2, 11.3 }[1]

[1] References from sections of the National Hospice and Palliative Care Organization Standards of Practice for Hospice Programs (2002) are cited in brackets, using their abbreviations as follows:

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Domain 5: Spiritual, Religious and Existential Aspects of Care (102, 103)

Guideline 5.1 Spiritual and existential dimensions are assessed and responded to based upon the best available evidence, which is skillfully and systematically applied. (32, 104)

Criteria:

- The interdisciplinary team includes professionals with skill in assessing (14, 104) and responding (105) to the spiritual and existential issues that pediatric and adult patients with life-threatening illnesses and conditions, and their families, are likely to confront.
- Regular, ongoing exploration (104) of spiritual and existential concerns occurs and is documented (including but not limited to life review, assessment of hopes and fears, meaning, purpose, beliefs about afterlife, guilt, forgiveness and life completion tasks). (39) Whenever possible a standardized instrument should be used. (80)
- A spiritual assessment is utilized to identify religious or spiritual/existential background, preferences, and related beliefs, rituals and practices of the patient and family. (106, 107)
- Periodic reevaluation of the impact of spiritual/existential interventions and patient-family preferences is documented. (36)
- Spiritual/existential care needs, goals and concerns are addressed (8, 103, 104) and documented, and support is offered for issues of life completion (104) in a manner consistent with the individual's and family's cultural and religious values. (106)
- Pastoral care and other palliative care professionals facilitate contacts with spiritual/religious communities, groups or individuals, as desired by the patient and/or family. Patients have access to clergy in their own religious traditions. (107)
- Professional and institutional use of religious symbols is sensitive to cultural and religious diversity. (107)
- The patient and family are encouraged to display their own religious/spiritual symbols. (107)
- The palliative care service facilitates religious or spiritual rituals as desired by patient and family, especially at the time of death. (109)
- Referrals to professionals with specialized knowledge or skills in spiritual and existential issues are made available when appropriate (e.g., to a chaplain familiar with or from the patient's own religious tradition). (37)
- A process for quality improvement is documented and leads to change in clinical practice. (17)

Selected References for Domain 5

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NHPCO Standards {HRCFCDCS 2, 5.2; IDT 7, 7.1, 11, 11.1, 11.2}[1]

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Domain 6: Cultural Aspects of Care

Guideline 6.1 The palliative care program assesses and attempts to meet the culture-specific needs of the patient and family.

Criteria:

- The cultural background, concerns and needs of the patient and their family are elicited and documented. (110-112)
- Cultural needs identified by team and family are addressed in the interdisciplinary team care plan. (110-112)
- Communication with patient and family is respectful of their cultural preferences regarding disclosure, truth-telling and decision-making. (113, 114)
- The program aims to respect and accommodate the range of language, dietary and ritual practices of patients and their families. (79, 114, 115)
- When possible, the team has access to and utilizes appropriate interpreter services. (116)
- Recruitment and hiring practices strive to reflect the cultural diversity of the community. (117)

Selected References for Domain 6

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NHPCO Standards {ARE 2, 2.1, 2.2; CCS 6.1, 11.1, 11.2, 12.4; HR 8, 8.1, 8.2; IDT 4, 4.1.9, 5, 5.1, 5.1.10, 7.1.3, 7.3}[1]

[1] References from sections of the National Hospice and Palliative Care Organization Standards of Practice for Hospice Programs (2002) are cited in brackets, using their abbreviations as follows:

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Domain 7: Care of the Imminently Dying Patient

Guideline 7.1 Signs and symptoms of impending death are recognized and communicated, and care appropriate for this phase of illness is provided to patient and family. (118)

Criteria:

- The patient's and family's transition to the actively dying phase is recognized, when possible, and is documented and communicated appropriately to patient, family and staff. (118)
- End-of-life concerns, hopes, fears and expectations are addressed openly and honestly (119) in the context of social and cultural customs (120) in a developmentally appropriate manner. (121)
- Symptoms at the end of life are assessed and documented with appropriate frequency (122) and are treated based on patient-family preferences. (8)
- The care plan is revised to meet the unique needs of the patient and family at this phase of the illness. (36) The need for higher intensity and acuity of care during the active dying phase is met and documented.
- Patient and family wishes regarding care setting for the death are documented. (20) Any inability to meet these needs and preferences is reviewed and addressed by the palliative care team.
- As patients decline, the hospice referral option will be introduced (or reintroduced) for those who have not accessed hospice services. (38)
- The family is educated regarding the signs and symptoms of approaching death (13, 118) in a developmentally-, age-, and culturally-appropriate manner. (119-121)

Selected References for Domain 7

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NHPCO Standards {CC 2.6, 3, 3.1, 3.2; CCS 1, 2, 3, 4, 5, 6, 7, 7.1, 7.2, 8, 9, 9.3, 10, 11, 11.1, 1.2, 11.3, 12, 12.1, 12.3, 13, 14, 15, 15.1, 15.315.4; HIFCCS 5, 5.1; HRCFCCS 5, 5.1}[1]

[1] References from sections of the National Hospice and Palliative Care Organization Standards of Practice for Hospice Programs (2002) are cited in brackets, using their abbreviations as follows:

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LG	Leadership and Governance		

Domain 8: Ethical and Legal Aspects of Care

Guideline 8.1 The patient's goals, preferences and choices are respected within the limits of applicable state and federal law, and form the basis for the plan of care. (8)

Criteria:

- The interdisciplinary team includes professionals with knowledge and skill in ethical, legal and regulatory aspects of medical decision-making. (123)
- The patient or surrogate's expressed wishes, in collaboration with the family and the interdisciplinary team, form the basis for the care plan. (8)
- The adult patient with decisional capacity determines the level of involvement of the family in decision-making and communication about the care plan. (124)
- Evidence of patient preferences for care is routinely sought and documented in the medical record. Failure to honor these preferences is documented and addressed by the team. (8, 34)
- Among minors with decision-making capacity, the child's views and preferences for medical care, including assent for treatment, should be documented and given appropriate weight in decision-making. When the child's wishes differ from those of the adult decision-maker, appropriate professional staff members are available to assist the child. (35, 124)
- The palliative care program promotes advance care planning in order to understand and communicate the patient's or an appropriate surrogate's preferences for care across the health care continuum. (34)
- When patients are unable to communicate, the palliative care program seeks to identify advance care directives, evidence of previously expressed wishes, values and preferences, and the appropriate surrogate decision-makers. The team must advocate the observance of previously expressed wishes of the patient or surrogate when necessary. (8, 34, 125)
- Assistance is provided to surrogate decision-makers on the legal and ethical bases for surrogate decision-making, including honoring the patient's known preferences, substituted judgment and best interest criteria. (8, 9, 125)

Guideline 8.2 The palliative care program is aware of and addresses the complex ethical issues arising in the care of persons with life-threatening debilitating illness. (123, 126)

Criteria:

- Ethical concerns commonly encountered in palliative care are recognized and addressed, using ethical principles to prevent or resolve ethical dilemmas, including: beneficence, respect for persons and self-determination, and associated regulatory requirements for truth-telling, capacity assessment, confidentiality, assent and permission for persons not of legal age to consent, and informed consent; attention to justice and nonmaleficence and associated avoidance of conflicts of interest. (123, 126) The team recognizes the role of cultural variation in the application of professional obligations, including truth-telling, disclosure, decisional authority and decisions to forgo therapy. (See Domain 6: Cultural Considerations). Attention must be paid to the role of children and adolescents in decision-making. (35)
- Care is consistent with the professional codes of ethics, and the scope, standards and code of ethics of palliative care practice are modeled on existing professional codes of ethics for all relevant disciplines. (128, 129)
- The palliative care team aims to prevent, identify and resolve ethical dilemmas related to specific interventions such as withholding or withdrawing treatments (including nutrition and hydration), instituting DNR orders, and the use of sedation in palliative care. (127, 130, 131)
- Ethical issues are documented; (39) referrals are made to ethics consultants or a committee, as appropriate. (132)

Guideline 8.3 The palliative care program is knowledgeable about legal and regulatory aspects of palliative care. (123)

Criteria:

- Palliative care practitioners are knowledgeable about legal and regulatory issues, including federal and state statutes and regulations regarding medical decision-making, advance care planning and directives; (123) the roles and responsibilities of surrogate decision-makers; (124, 125) appropriate prescribing of opioids and other controlled substances; (51) pronouncing death; (134, 135) request for autopsy and organ transplant; (136) and associated documentation in the medical record.
- Patients and families are routinely advised of the need to seek professional advice on creating or updating property wills and guardianship agreements. (133)

Selected References for Domain 8

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NOTE: An easy reference to the various sections of the NHPCO Standards of Practice for Hospice Programs (2000) is provided in brackets at the end of each domain.

NHPCO Standards {ARE 3, 3.2, 3.3, 3.4, 3.5, 3.6, 6.2, 8, 8.1, 8.2; CCS 14.1, 14.2; IDT 11; 15.1}[1]

[1] References from sections of the National Hospice and Palliative Care Organization Standards of Practice for Hospice Programs (2002) are cited in brackets, using their abbreviations as follows:

ARE	Access, Rights, Ethics	MI	Management of Information
BCS	Bereavement Care and Services	PI	Performance Improvement and Outcomes Measurement
CC	Coordination and Continuity of Care	SIC	Safety and Infection Control
CCS	Clinical Care and Services	HIF	Hospice Inpatient Facility
HR	Human Resources	NF	Nursing Facility Hospice Care
IDT	Interdisciplinary Team	HRCF	Hospice Residential Care Facility
LG	Leadership and Governance		

CONCLUSION

Palliative care services aim to support patients of all ages with debilitating and life-threatening illness, and their families, through the full course of the illness, regardless of its duration, until cure or until death, and through the bereavement period. Palliative care is delivered through skilled and interdisciplinary attention to pain and other distressing symptoms; emotional, spiritual and practical support; assistance with complex medical decision-making; and coordination across the continuum of health care settings. The goal is to help the patient and family achieve the best possible quality of life in accordance with their values, needs and preferences. These guidelines for quality palliative care programs represent a consensus opinion of the major palliative care organizations and leaders in the United States, and are based both on the available scientific evidence and expert professional opinion.

Clinical practice guidelines such as these have become the accepted means of promoting consistency, comprehensiveness and quality across many domains of health care. The widespread adoption of these guidelines in the United States will help to establish palliative care as an integral component of the health care of persons living with life-threatening and debilitating chronic illness. It is hoped that these Clinical Practice Guidelines for Palliative Care will encourage access to high-quality palliative care that patients and their families can come to expect and rely upon.

Notes on References

The following are selected references, divided by section, that provide the evidence base for the National Consensus Project Guidelines for Quality Palliative Care.[1] The references focus on well-designed, useful studies, both observational and experimental, as well as published consensus statements and expert opinions. Particularly in Domains 2 and 3 (the sections on physical and psychological distress), only a small portion of the relevant literature is provided.

All participants in the National Consensus Project (NCP) were invited to suggest key references. We also conducted a variety of literature searches in Medline and the Cochrane Collaboration, and reviewed many articles and textbooks, primarily in the fields of medicine and nursing. Where experimental evidence of good quality care exists, it is cited. Other references reflect the expert opinion of consensus efforts, professional organizations and experts in the field. This document does not represent an exhaustive review of the literature relevant to hospice and palliative care. For the Introduction and Domain 1: Structure and Processes of Care, which address fundamental features of palliative care, we provide thorough documentation, while in the sections on physical or psychological distress, key articles or recent summaries that complement the many excellent textbooks on palliation are cited under General References.

The National Hospice and Palliative Care Organization provided a "cross-walk" of the NCP guidelines with their Standards of Practice for Hospice Programs (2002). References to this document are listed in brackets.

A Note on the "State of the Science"

While many key concepts about end-of-life care were well articulated 40 years ago in the founding days of the hospice movement, an array of excellent studies can be cited in the past few decades during which palliative care has developed as a distinct discipline. Research that confirms, refines, extends and occasionally refutes hospice notions has blossomed, and the growth of the evidence base has been impressive in recent years. In selected areas, particularly in pain and symptom management, as well as in some aspects of psychological care and bereavement, well-designed experimental studies have begun to appear. Meanwhile, instruments appropriate for measuring palliative care outcomes, such as patient and family satisfaction, symptom distress, functional status, mood and quality of life, continue to improve.

[1] Note: For complete citations, go to the bibliography at *www.nationalconsensusproject.org/guidelines.*

The elements of palliative care have also become better defined and thus more subject to evaluation studies. For example, the use of artificial nutrition and hydration near the end of life is a practice generally shunned by hospice pioneers, and still often considered inappropriate for most dying patients. However, the utility of these interventions in selected patients is now recognized, but well-designed experimental studies are lacking. The randomized controlled trial has been difficult to carry out in the field of palliative care — being too intrusive and time consuming to be performed with very sick persons or with families under great stress. New measurement methodologies and study designs are needed.

Palliative care shares with other fields of medicine and nursing many well-recognized standards of care (e.g., continuity, communication, patient-centeredness) that have not been subjected to extensive, careful experimental verification. Some of the central tenets of the field — for example, interdisciplinary care, teamwork, patient-/family-centered decision-making, and an integrated, comprehensive approach to assessing and treating all forms of suffering — have never been validated in experimental studies. Demonstration projects and multi-center research will be necessary to test the utility of these care approaches in large patient populations.

The failings of the current health care system however, are well documented. The best documented and most consistent finding of numerous studies over the past few decades has been confirmation of the original observations of the founders of the hospice movement that inadequacies in symptom control, psychosocial and spiritual support (including bereavement care), shared decision-making, and attention to alternative sites of care fall short of common-sense standards for quality of care, leaving many observers (clinicians, patients, and family members) dissatisfied. A broad range of problems have been identified and extensively documented. These studies constitute the early descriptive phase of palliative care research. At the same time, hospice and palliative care have been shown to provide an alternative that consistently enhances patient and family satisfaction, often improves physical and emotional distress and regularly leads to cost-savings.

Many studies, mostly using survey methodology, offer a broad overview of this process, but except for studies of symptom management, there is a dearth of detailed examination of current practices and the impact of discrete interventions. For instance, late referrals to hospice programs in the United States have been decried for many years by proponents of palliative care. But the factors leading to this pattern, the impact of late referral on key outcomes and the effectiveness of various remedies have not been studied. More detailed qualitative and cross-cultural studies could be useful for understanding the forces that lead to this situation.

The science of palliative care is moving beyond its early, largely descriptive phase of development in which problems in end-of-life care were identified and solutions, although described, were not necessarily carefully tested.

References, by section

Introduction

1. **Growth of hospice and palliative care programs in the United States:** (Robert Wood Johnson Foundation,Fund MM 2000;Billings JA,Pantilat S 2001;Pan CX, Morrison RS 2001;White KR, Cochran CE 2002;National Hospice and Palliative Care Organization 2003;Pantilat SZ,Billings JA 2003)

2. **Palliative care is concurrent care, available from the time of diagnosis, not an alternative to "conventional" care:** (Ryndes T 1995;Portenoy RK 1998;MacDonald N 2002;Meyers FJ,Linder J 2003;Selwyn PA,Forstein M 2003)

3. **Key recent reports promote the development of palliative care and hospice:** (Field MJ,Cassel CK 1997; Institute of Medicine 2001;American Association of Colleges of Nursing 2002;Field MJ, Behrman DE 2003;Jennings B, Ryndes T 2003)

4. **Other important reports promote palliative care and hospice:** (Hastings Center 1987;American Nurses Association 1991e;American Nurses Association 1991b;American Nurses Association 1991c;American Nurses Association 1991d;American Nurses Association 1991a;Children's Hospice International 1993;American Geriatrics Society Ethics Committee 1994;American Nurses Association 1994a;American Nurses Association 1994b;Jacox A., Carr D.B. 1994;American Pain Society Quality of Care Committee 1995;American Academy of Neurology Ethics and Humanities Subcommittee 1996;Council on Scientific Affairs AMA 1996;Hospice Nurses Association 1996;Higginson IJ, Sen-Gupta G 1997;Hospice and Palliative Nurses Association 1997;McSkimming SA, Super M 1997;National Council For Hospice And Specialist Palliative Care Services 1997;National Hospice Organization Standards and Accreditation Committee 1997;American Board of Internal Medicine Committee on Evaluation of Clinical Competence 1998;American Geriatrics Society Panel on Chronic Pain in Older Persons 1998;American Society of Clinical Oncology End of Life Task Force 1998;Ferrell BR, Virani R 1998;American Association of Critical-Care Nurses 1999;Emanuel LL, von Gunten CF 1999;Ferrell B.R., Grant M. 1999;Grossman SA, Benedetti C 1999;Hospice and Palliative Nurses Association 1999;National Comprehensive Cancer Network 1999;National Task Force on End-of-Life Care in Managed Care 1999;Oncology Nursing Society 1999;American Academy of Pediatrics, Committee on Bioethics and Committee on Hospital Care 2000;American Academy of Pediatrics Committee on Psychosocial Aspects of Child and Family Health 2000;American Medical Directors Association 2000;Bednash G,Ferrell B 2000;Joint Commission on Accreditation of Healthcare Organizations 2000;National Hospice and Palliative Care Organization 2000;Brown ST, Blacker S 2001;Foley KM,Gelband H 2001;Hospice and Palliative Nurses Association 2001;National Advisory Committee on Palliative Care 2001;National Hospice and Palliative Care Organization 2001a;National Hospice and Palliative Care Organization 2001b;Roundtable O 2001;American Academy of Pediatrics and the American College of Emergency Physicians 2002;American College of Surgeons 2002;Ferris F. D., Balfour H. M. 2002;Hospice and Palliative Nurses Association 2002e;Hospice and Palliative Nurses Association 2002b;Hospice and Palliative Nurses Association 2002d;Hospice and Palliative Nurses Association 2002f;Hospice and Palliative Nurses Association 2002a;Hospice and Palliative Nurses Association 2002c;Hospice and Palliative Nurses Association,American Nurses Association 2002;Last Acts 2002;Medicare Payment Advisory Commission (MedPAC) 2002;Moon M,Boccutti C 2002;National Comprehensive Cancer Network 2002;National Hospice and Palliative Care Organization 2002;National Institute of Health Consensus Development Program 2002;American Medical Association Council on Ethics and Judicial Affairs 2003;American Nurses Association 2003;Fins JJ, Peres JR 2003;Hopper SS 2003;Hospice and Palliative Nurses Association 2003;National Comprehensive Cancer Network 2003b;National Comprehensive Cancer Network 2003a;National Hospice and Palliative Care Organization 2003;Hospice and Palliative Nurses Association 2004b;Hospice and Palliative Nurses Association 2004a;American Pain Society Task Force on Pain,Symptoms and End of Life Care undated;Smits HL, Furletti M undated)

5. **Definition of palliative care:** (Finlay IG,Jones RV 1995;Billings JA 1998;National Council For Hospice And Specialist Palliative Care Services 2002;World Health Organization 2002)

6. **Modified from (World Health Organization 2002)**

7. **A broad patient population is appropriate for palliative care:** (Field MJ,Cassel CK 1997;Mann SM,Welk TA 1997;Post LF,Dubler NN 1997;American Association of Colleges of Nursing 2002;Field MJ, Behrman DE 2003)

8. **Patient-and family-centered care; the importance of eliciting and responding to patient and family values and goals:** (Kristjanson LJ 1986;Kristjanson LJ 1989;Goldberg R, Guadagnoli E 1990;Teno JM, Mor V 1991;Kristjanson LJ,Ashcroft T 1994;Murphy DJ, Burrows D 1994;1995;Teno JM, Hakim RB 1995;Kristjanson LJ, Sloan JA 1996;Greisinger AJ, Lorimor RJ 1997;Kristjanson LJ, Leis A 1997;Kristjanson LJ, Nikoletti S 1998;Krumholz HM, Phillips RS 1998;Singer PA, Martin DK 1999a;Singer PA, Martin DK 1999b;Teno JM 1999;Emanuel EJ, Fairclough DL 2000;Norton SA,Talerico KA 2000;Phillips RS,

Hamel MB 2000;Steinhauser KE, Christakis NA 2000;Steinhauser KE, Clipp EC 2000;Tolle SW, Tilden VP 2000;Andrews SC 2001;Bruera E, Sweeney C 2001;Price KJ,Kish SK 2001;Teno JM, Casey VA 2001;Contro N, Larson J 2002;Teno JM, Fisher ES 2002;American Academy of Pediatrics and the Institute for Family-Centered Care 2003;Carline JD, Curtis JR 2003;Teno JM, Clarridge BR 2004) {ARE 3, 3.1-3.3, 3.5, 3.6, 8, 14, 14.1, 14.2 HIFCCS 3; HIFSIC 1,1.1-1.7, 5; HRCFSIC 1, 1.1-1.9, 2, 2.1-2.6, 3, 3.1, 5, 7, 7.1-7.4}. See also information-sharing (13), site of care (20, 26), advance care planning (34), and Domain 4: Social Aspects of Care, Domain 5: Spiritual, Religious and Existential Aspects of Care, and Domain 6: Cultural Aspects of Care.

9. **Professional assistance with decision-making:** (Murphy DJ, Burrows D 1994;Morrison RS, Zayas LH 1998;Braddock CH, 3rd., Edwards KA 1999;Baggs JG,Schmitt MH 2000;Borum ML, Lynn J 2000;Hopp FP,Duffy SA 2000;Foster LW,McLellan LJ 2002;Gattellari M, Voigt KJ 2002;Chao C, Studts JL 2003;Teno JM, Clarridge BR 2004)

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11. **Interdisciplinary teamwork, interdisciplinary assessment, and team education:** (Given B,Simmons S 1977;Twycross RG 1990;Higginson IJ, Wade AM 1992;Shortell SM, Zimmerman JE 1994;Norsen L, Opladen J 1995;Council on Scientific Affairs AMA 1996;Billings JA,Block S 1997;Coyle N 1997;Field MJ,Cassel CK 1997;Higginson IJ,Hearn J 1997;O'Neill B,Fallon M 1997;Ross DD, O'Mara A 1997;American Board of Internal Medicine Committee on Evaluation of Clinical Competence 1998;Block S,Billings JA 1998;Ferrell BR, Virani R 1998;Ramirez A, Addington-Hall J 1998;Baggs JG, Schmitt MH 1999;Emanuel LL, von Gunten CF 1999;Ferrell B.R., Grant M. 1999;Lynn J,Harrold J 1999;Steel K, Ribbe M 1999;Abrahm JL 2000;Benedetti C, Brock C 2000;Francke AL 2000;Freeborne N, Lynn J 2000;National Hospice and Palliative Care Organization 2000;Smeenk FW, de Witte LP 2000;Sommers LS, Marton KI 2000;Emanuel LL, Alpert HR 2001;Ferrell B,Coyle N 2001;Glass E, Cluxton D 2001;Krammer, Ringel SP 2001;Mularski RA, Bascom P 2001;Smith SA 2001;Zwarenstein M, Reeves S 2001;American Association of Colleges of Nursing 2002;Brown-Hellsten M, Hockenberry-Eaton M 2002;Higginson IJ, Finlay I 2002;Hospice and Palliative Nurses Association 2002d;Hospice and Palliative Nurses Association 2002f;Abrahm JL 2003;De Conno F, Panzeri C 2003;Field MJ, Behrman DE 2003;Haggerty JL, Reid RJ 2003;Higginson IJ, Finlay IG 2003;Hospice and Palliative Nurses Association 2003;Matzo ML,Sherman DW 2003;Smith TJ, Coyne P 2003;Lickiss JN, Turner KS 2004) {IDT 1.1, 14, 14.1,14.2; HR 4, 4.1, 4.2, 4.4; CC 2.2;IT 1}

12. **Attention to relief of all forms of suffering:** (Cassell ES 1982;Cassell EJ 1991;Cassell EJ 1992;Cassell EJ 1999;National Hospice and Palliative Care Organization 2000;Thompson G,McClement S 2002)

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16. **Equitable access to services:** (National Hospice and Palliative Care Organization 2000;Smeenk FW, de Witte LP 2000;Meier D. E. 2002;Jennings B, Ryndes T 2003)

17. **Quality improvement and quality assurance:** (McCarthy M,Higginson I 1991;Higginson I 1993;McWhinney IR, Bass MJ 1994;American Pain Society Quality of Care Committee 1995;Coyne PJ 1995;Bruera E 1996b;Campbell ML 1996;Hearn J,Higginson IJ 1997;Lynn J 1997;National Hospice and Palliative Care Organization 1997;National Hospice Organization Standards and Accreditation Committee 1997;Rudberg MA, Teno JM 1997;Scanlon C 1997;Teno JM, Landrum K 1997;American Board of Internal Medicine Committee on Evaluation of Clinical Competence 1998;Donaldson MS,Field MJ 1998;Robbins M 1998;United Hospital Fund 1998;Du Pen SL, Du Pen AR 1999;Teno JM,Coppola KM 1999;Lynn J 2000;Morrison RS, Siu AL 2000;Reese D, Raymer M 2000;Rosenfeld K,Wenger NS 2000;Teno J 2000;Ellershaw J, Smith C 2001;Hermann CP 2001;Institute of Medicine Committee on Quality Health Care in America, Institute of Medicine, 2001;Kizer KW 2001b;Kizer KW 2001a;Teno JM, Clarridge B 2001;Teno JM, Field MJ 2001;Epstein RM,Hundert EM 2002;Hanks GW, Robbins M 2002;Last Acts 2002;Lynn J, Nolan K 2002;National Quality Forum 2002;Shaughnessy PW, Hittle DF 2002;Steinhauser KE, Bosworth HB 2002;Steinhauser KE, Clipp EC 2002;Thompson G,McClement S 2002;Aspinal F, Addington-Hall J 2003;McGlynn EA, Cassel CK 2003;National Quality Forum 2003) {PI 1.1, 2, 2.1-2.3, 3.2, 4, 4.1, 4.3, 4.4, 5.2, 5.3, 6, 6.1,6.2}

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26 **Where people die and where they want to die:** (Teno JM 2003;Hansen LC, Henderson M 2002;Wennberg J, Copper M 1998;Kemper P, Murtaugh CM 1991;Bruera E, Russell N 2002;Furst CJ, Doyle D 2004;Ratner E, Norlander L 2001;Jordhoy MS, Foyers P 2000;Haines A, Booroff A 1986;Teno JM, Clarridge BR 2004;Weitzen S, Teno JM 2003) {CCS 6, 13; CC 3, 3.1,3.2}

27. **Problems of burdensome technologies:** (Teno JM, Fisher ES 2002)

28. **Need for education about palliative care for all health professionals, especially in hospitals:** (Sanson-Fisher R,Maguire P 1980;Sanson-Fisher R, Fairbairn S 1981;Maguire P, Fairbairn S 1986b;Maguire P, Fairbairn S 1986a;Arnold RM, Forrow L 1988;Maguire P,Faulkner A 1988;Weissman DE 1991;Billings JA 1993;Bird J, Hall A 1993;Covinsky KE, Goldman L 1994;1995;Tulsky JA, Chesney MA 1995;Billings JA,Block S 1997;Bruera E, Selmser P 1997;Campbell ML,Frank RR 1997;Field MJ,Cassel CK 1997;Manias E, Kristjanson L 1997;Ross DD, O'Mara A 1997;Seely JF, Scott JF 1997;Block S,Billings JA 1998;Ferrell BR, Virani R 1998;Oneschuk D,Bruera E 1998;Danis M, Federman D 1999;Emanuel LL, von Gunten CF 1999;Ersek M, Kraybill BM 1999;Ferrell B, Virani R 1999a;Ferrell B, Virani R 1999b;Ferrell B. R., Grant M. 1999;Ferrell BR, Juarez G 1999;Linder JF, Blais J 1999;Steel K, Ribbe M 1999;Weissman DE, Block SD 1999;Ferrell B, Virani R 2000b;Ferrell BR, Virani R 2000;Fins JJ,Nilson EG 2000;Lynn J, Schuster JL 2000;Meekin SA, Klein JE 2000;Meisel A, Snyder L 2000;Oneschuk D, Hanson J 2000b;Sahler OJ, Frager G 2000;Tolle SW, Tilden VP 2000;Wenger NS, Phillips RS 2000;Faulkner A, Argent J 2001;Jubelirer SJ, Welch C 2001;Mularski RA, Bascom P 2001;Murphy-Ende K 2001;Novak B, Kolcaba K 2001;Ross DD, Fraser HC 2001;Weissman DE, Mullan P 2001;American Association of Colleges of Nursing 2002;Aronson SG,Kirby RW 2002;Billings JA, Block SD 2002;Ferrell BR,Borneman T 2002;Maguire P,Pitceathly C 2002;Mullan PB, Weissman DE 2002;Spiegel MJ, Meier DE 2002;Weissman DE,Block SD 2002;Weissman DE, Mullan PB 2002;Back AL, Arnold RM 2003;Keay TJ, Alexander C 2003;Razavi D, Merckaert I 2003;Sullivan AM, Lakoma MD 2003)

29. **Hospice improves nursing home outcomes:** (Baer WM,Hanson LC 2000;Gage B, Miller S 2000;Miller SC, Gozalo P 2000)

30. **Professional organizations, programs and studies supporting improved end-of-life care in nursing homes:** (Castle NG, Mor V 1997;Bernabei R, Gambassi G 1998;Bradley EH, Peiris V 1998;Petrisek AC,Mor V 1999;Steel K, Ribbe M 1999;American Medical Directors Association 2000;Hanson LC,Henderson M 2000;Miller S,2000;Zerzan J, Stearns S 2000;DeSilva DL, Dillon JE 2001;Miller SC,Mor V 2001;Hanson LC, Henderson M 2002;Miller SC,Mor VN 2002;Reynolds K, Henderson M 2002;Keay TJ, Alexander C 2003;Meador R, Hegeman C 2003;Miller SC, Mor V 2003)

31. **Palliative care guidelines from other health care systems:** See also Appendix 1 (Palliative Care Australia 1998;Palliative Care Australia 1999;Freeborne N, Lynn J 2000;Palliative Care Australia 2000;National Advisory Committee on Palliative Care 2001;New Zealand Ministry of Health 2001;Ferris F. D., Balfour H.M. 2002;Association for Palliative Medicine of Great Britain and Ireland)

32. **Evidence-based guidelines and improvement of palliative care practice over time:** (Higginson I, Wade A 1990;Jacox A., Carr D.B. 1994;Higginson IJ, Hearn J 1996;Kuebler KK, Dahlin C 1996;Glance LG, Osler T 1998;Grossman SA, Benedetti C 1999;National Comprehensive Cancer Network 1999;National Comprehensive Cancer Network 2003b)

Domain 1: Structure and Processes of Care

33. **Assessment requires complete review of history, physical examination, laboratory studies, records, etc.:** (Bruera E 1996a;Dunn GP 2001) {CCS 1.2, 1.3, 3, 6; IDT 3.1}

34. **Advance care planning:** (American Nurses Association 1991c;American Nurses Association 1991d;Lynn J,Teno JM 1993;Teno J, Lynn J 1993;Teno JM, Sabatino C 1993;Cherny NI,Portenoy RK 1994;Teno JM, Lynn J 1994;Teno JM, Nelson HL 1994;Tulsky JA, Chesney MA 1995;Covinsky KE, Landefeld CS 1996;Davis A 1996;Eleazer GP, Hornung CA 1996;Hakim RB, Teno JM 1996;Hamel MB, Phillips RS 1996;Miles SH, Koepp R 1996;Murphy ST, Palmer JM 1996;Teno JM,Lynn J 1996;Cleary JF,Carbone PP 1997;Galanos AN, Pieper CF 1997;Hauser JM, Kleefield SF 1997;Hofmann JC, Wenger NS 1997;Mor V, Intrator O 1997;Teno J, Lynn J 1997;Bradley EH, Peiris V 1998;Hammes BJ,Rooney BL 1998;Morrison RS, Zayas LH 1998;Teno JM, Stevens M 1998;Carmin CN, Pollard CA 1999;Hamel MB, Davis RB 1999;Hamel MB, Teno JM 1999;Hamel MB, Lynn J 2000;Teno JM, Fisher E 2000;Teno JM, Harrell FE, Jr. 2000;Walsh D, Donnelly S 2000;Wenger NS, Phillips RS 2000;Wu AW, Yasui Y 2000;Happ MB, Capezuti E 2002;Kolarik RC, Arnold RM 2002;Schwartz CE, Wheeler HB 2002;Yurk R, Morgan D 2002;Allen RS, DeLaine SR 2003;Clarfield AM, Gordon M 2003;Mitchell SL 2003;Scott JT, Harmsen M 2003)

35. **Assessing and treating children as patients and as family members:** (McCullough PK 1992;Perrin JM, Shayne, M., and Bloom, S 1993;McCue K 1994;Mayo S 1996;Sourkes BM 1996;Kunin H 1997;Carmin CN, Pollard CA 1999;International Work Group on Death, Dying, and Bereavement, Work Group on Palliative Care for Children 1999;American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care 2000;Collins JJ, Byrnes ME 2000;Sahler OJ, Frager G 2000;Wolfe J 2000;Wolfe J, Grier HE 2000;Armstrong-Dailey A,Zarbock S 2001;Hinds PS, Oakes L 2001;Brown-Hellsten M, Hockenberry-Eaton M 2002;Collins JJ 2002;Rauch P,Arnold R 2002;Rauch PK, Muriel AC 2002;Depaola SJ, Griffin M 2003;Higginson IJ,Thompson M 2003;Scott JT, Harmsen M 2003;Solomon MZ, Browning D 2003;Tadmor CS, Postovsky S 2003) {ARE 3.3, 3.4; CCS 1.2, 1.3, 2.1, 3, 3.1- 3.3, 8, 10, 11, 13}

36. **Regular reassessment to recognize shifting and multiple priorities:** (American Society of Clinical Oncology End of Life Task Force 1998;Morita T, Tsunoda J 1999;American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care 2000;Emanuel EJ, Fairclough DL 2000;Billings JA, Block SD 2002;Hilden JM, Tobin DR 2002) {CC 2.2, 2.4, IDT 11.2, 12, 12.1-12.4; CCS 1-15, 15.1}

37. **Access to specialists:** (Giordano M 2000;Friedman BT, Harwood MK 2002;Hanks GW, Robbins M 2002;Payne S,Haines R 2002;Lloyd-Williams M 2003;Miller SC, Kinzbrunner B 2003){CSS 5.4; IDT 6}

38. **Involve patient and family, community resources, and other supports in developing and carrying out the care plan. Palliative care programs coordinate and collaborate with hospice and other community programs, including referrals to community resources (school, work, transportation, rehabilitation, assistance with obtaining medications and medical equipment, financial support):** (Mor V 1987;Mor V, Greer DS 1988;Tulsky JA,Lo B 1992;Tulsky JA,Fox E 1996;Dowdy MD, Robertson C 1998;Schneiderman LJ, Gilmer T 2000;Friedman BT, Harwood MK 2002;Hanks GW, Robbins M 2002;Meier D. E. 2002;von Gunten CF 2002a;Lee S,Kristjanson L 2003;Miller SC, Kinzbrunner B 2003;Schneiderman LJ, Gilmer T 2003;Cassidy JP,Davies DJ 2004) { RE 1.4; CCS 5.4;IDT 6, 6.3; CCS 14, 14.1, 14.2} {IDT 6, 6.3; 7.1, 11.1; CCS 14, 14.1, 14.2 Change to 53}

39. **Documentation of assessment and care plan:** (Higginson I,McCarthy M 1989;Bruera E, Kuehn N 1991;Du Pen SL, Du Pen AR 1999;Collins JJ, Byrnes ME 2000;Nelson JE, Meier DE 2001;Tranmer JE, Heyland D 2003) {ARE 8; CC1.1, 2, 2.3; IDT 12.1, 12.4, 13.3; MI 3.3}

40. **Services are available 24-hours-a-day, 7-days-a-week:** (Lynn J, Schuster JL 2000) {CC 1, 1.1-1.3, 1.5; HIF CCS 2; HFCF CCS 1, 1.1, 1.2, 2; NF ARE, 1.1}

41. **Respite services are available:** (Cumming M 1993;Ingleton C, Payne S 2003)

42. **Overall review of care occurs in weekly team meetings, while regular meetings allow for discussion of quality of care:** {IDT 12.1, 12.2, 15.5; HR 1.1}

43. **Team leaders are trained for their role:** {LG 8.2, 12; HR 9.2}

44. **Policies for timely intake are documented:** {CC 2.1; MI 1.1, 1.2}

45. **Volunteers may be included:** (Mount BM 1992;Craig M 1994;Fusco-Karmann C, Gangeri L 1996;Lemkin P 2001;Doyle D 2003){HR 7.5}

46. **Staff are supported in obtaining ongoing professional education, including discipline-specific training:** (Mount BM 1986;Block SD,Billings JA 1995;Brown-Saltzman K 1998;Ferrell BR, Virani R 1998;Miller PJ, Hedlund SC 1998;Christ GH,Sormanti M 1999;Ferrell B, Virani R 1999a;Ferrell B, Virani R 1999b;Ferrell B. R., Grant M. 1999;Ferrell BR, Juarez G 1999;Saunderson EM,Ridsdale L 1999;Csikai EL,Bass K 2000;Ferrell BR,Virani R 2000;Ferrell BR, Virani R 2000;Reese D, Raymer M 2000;Meier DE, Back AL 2001;Roff S 2001;American College of Surgeons 2002;Back AL, Starks H 2002;Ferrell BR,Borneman T 2002;Leipzig RM, Hyer K 2002;Hospice and Palliative Nurses Association 2004b;Hospice and Palliative Nurses Association 2004a;Monroe B 2004) {HR 3.5, 3.6, 4, 4.1-4.5, 5, 5.1- 5.4, 6, 6.1-6.3, 7, 7.1, 7.2, 9, 9.1, 9.2}

47. **Staff support is provided, including regular meetings:** (Smith SP,Varoglu G 1985;Vachon MS 1995;Vachon ML 1998;Kristjanson LJ, McPhee I 2001;Vachon MLS 2004) {HR 4.5}

48. **For care outside the home, patients and families are provided with a safe, home-like atmosphere that allows for privacy, cooking, visiting at all times, and access for children:** {HIFCCS 3; HIFSIC 1,1.1-1.7, 5; HRCFSIC 1, 1.1-1.9, 2, 2.1-2.6, 3, 3.1, 5, 7, 7.1-7.4}

Domain 2: Physical Aspects of Care

I. PAIN

49. **Pain in end-of-life care:** (Bruera E, Carraro S 1986;Brenneis C, Michaud M 1987;Ventafridda V, Ripamonti C 1987;Berde C, Ablin A 1990;Ripamonti C,Bruera E 1991;Zaw-Tun N,Bruera E 1992;Portenoy RK 1993;Ferrell BR, Rhiner M 1994a;Ferrell

BR, Rhiner M 1994b;Jacox A., Carr D. B. 1994;Jacox A., Carr D.B. 1994;Portenoy RK, Thaler HT 1994;Collins JJ, Grier HE 1995;Portenoy RK 1995;Vigano A, Fan D 1996;World Health Organization 1996;Lawlor P, Turner K 1997;Lawlor P, Walker P 1997;Lynn J, Teno JM 1997;Portenoy RK 1997b;Portenoy RK 1997a;Ripamonti C, Zecca E 1997;Lawlor PG, Turner KS 1998;Morrison RS, Ahronheim JC 1998;Ripamonti C, De Conno F 1998;Vigano A, Bruera E 1998;World Health Organization 1998a;McCaffery M,Pasero C 1999;American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care 2000;Milch RA 2000;Thorns A,Sykes N 2000;Zekry HA,Bruera E 2000;Zeppetella G 2000;Abrahm J 2001;Coluzzi PH, Schwartzberg L 2001;Greenstreet W 2001;McCracken LM, Matthews AK 2001;Mitten T 2001;American Association of Colleges of Nursing 2002;Choi YS,Billings JA 2002;Mercadante S, Radbruch L 2002;National Institute of Health Consensus Development Program 2002;Radbruch L, Sabatowski R 2002;Ripamonti C,Bianchi M 2002;Smith TJ, Staats PS 2002;Thompson G,McClement S 2002;Briggs M,Nelson EA 2003;Mailis A,Furlan A 2003;Quigley C,Wiffen P 2003;Ribeiro MDC,Zeppetella G 2003;Sittl R, Griessinger N 2003;Zeppetella G,Ribeiro M 2003) {CCS 1, 1.2, 1.3, 2, 2.1, 2.5, 3, 3.1, 3.2, 10, 14; IDT 11.2, 12, 12.1, 12.2, 12.3, 12.4; MI 3.3}

50. **Pain assessment:** (Portenoy RK,Hagen NA 1990;Fothergill-Bourbonnais F,Wilson-Barnett J 1992;Johnston CC, Stevens B 1993;Parmelee PA, Smith B 1993;Savedra MC, Holzemer WL 1993;Bruera E 1994;Ferrell BA 1995;Bruera E, Pereira J 1996;Parmelee PA 1996;Merkel S, Voepel-Lewis T 1997;Portenoy RK 1997a;Chambers CT, Reid GJ 1998;Ferrell BR, Virani R 1998;Morrison RS, Ahronheim JC 1998;Portenoy RK,Lesage P 1999;Collins JJ, Byrnes ME 2000;Francke LS, Greenberg CS 2000;Joint Commission on Accreditation of Healthcare Organizations 2000;Sulmasy DP, Ury WA 2000;American Academy of Pediatrics. Committee on Psychosocial Aspects of Child and Family Health 2001;Breau LM, Camfield C 2001;Mercadante S,Portenoy RK 2001c;Mercadante S,Portenoy RK 2001a;Mercadante S,Portenoy RK 2001b;Collins JJ, Devine TD 2002;Bruera E,Castro M 2003;Miller SC, Kinzbrunner B 2003) {CCI1.1,2 ;IDT 13.3}

51. **Pain treatment:** (Bruera E, Carraro S 1986;Brenneis C, Michaud M 1987;Bruera E, Brenneis C 1988;Bruera E 1991;Bruera E 1992;Walsh TD, MacDonald N 1992;Portenoy RK 1993;Bruera E 1994;Cleeland CS, Gonin R 1994;Jacox A., Carr D. B. 1994;Jacox A., Carr D.B. 1994;Breitbart W, Bruera E 1995;Portenoy RK 1995;Thomas Z,Bruera E 1995;Bozzetti F, Amadori D 1996;Breitbart W, McDonald MV 1996;Lipman AG 1996;Rosenfeld B, Breitbart W 1996;Watanabe S, Belzile M 1996;Cleeland CS, Gonin R 1997;Portenoy RK 1997b;Ripamonti C,Bruera E 1997;Ripamonti C,De Conno F 1997;Watanabe S, Carmody D 1997;Bernabei R, Gambassi G 1998;Watanabe S, Pereira J 1998;Du Pen SL, Du Pen AR 1999;Grossman SA, Benedetti C 1999;Manfredi PL, Shenoy S 2000;Tarumi Y, Watanabe S 2000;American Academy of Pediatrics. Committee on Psychosocial Aspects of Child and Family Health 2001;Cherny N, Ripamonti C 2001;Filiberti A, Ripamonti C 2001;Gibson J,Grealish L 2001;Manfredi PL, Gonzales GR 2001;American Geriatric Society Panel on Persistent Pain in Older Persons 2002;Barnes EA,Bruera E 2002;Barnes EA, Palmer JL 2002;Mercadante S, Villari P 2002;Moryl N, Santiago-Palma J 2002;Bell R, Eccleston C 2003;Harris JT, Suresh Kumar K 2003;Howard RF 2003;Kearns GL, Abdel-Rahman SM 2003;Lander JA,Weltman BJ;Lussier D 2003;Mailis A,Furlan A 2003;Martinez MJ, Roque M 2003a;Nicholson A, Davies AN 2003;Reid CM, Davies AN 2003;Ribeiro MDC,Zeppetella G 2003;Siden H,Nalewajek 2003;Tremont-Lukats IW, Teixeira GM;Wiffen P, Collins S;Zeppetella G,Ribeiro M 2003)

II. OTHER PHYSICAL SYMPTOMS

52. **Physical symptoms: general:** (Cassell ES 1982;Cassel CK 1984;Bruera E, Carraro S 1986;Brenneis C, Michaud M 1987;Bruera E, Brenneis C 1988;Ventafridda V, Ripamonti C 1990;Bruera E, Fainsinger R 1991;Bruera E 1992;Addington-Hall J, Lay M 1995;Bozzetti F, Amadori D 1996;Cleary JF,Carbone PP 1997;Conill C, Verger E 1997;Hearn J,Higginson IJ 1997;McClement SE, Woodgate RL 1997;Neuenschwander H, Bruera E 1997;Campbell M 1998;Ng K,von Gunten CF 1998;O'Brien T, Welsh J 1998;World Health Organization 1998b;Cassell EJ 1999;Emanuel LL, von Gunten CF 1999;Ferrell B.R., Grant M. 1999;Kemp C 1999;Shuster JL, Jr., Breitbart W 1999;Twycross R 1999;Wrede-Seaman L 1999;Bednash G,Ferrell B 2000;Bernard SA,Bruera E 2000;Collins JJ, Byrnes ME 2000;Keay TJ,Schonwetter RS 2000;Leland JY 2000;McCallum DE, Byrne P 2000;Waller A,Caroline NL 2000;Walsh D, Donnelly S 2000;Ellershaw J, Smith C 2001;Emanuel LL, Alpert HR 2001;Ferrell B,Coyle N 2001;Hermann C,Loonery S 2001;Matzo ML,Sherman DW 2001;Pierucci RL, Kirby RS 2001;Smith SA 2001;Berger A, Portenoy RK 2002;Coll PP, Duffy JD 2002;Pantilat SZ 2002;World Health Organization 2002;Abrahm JL 2003;Drake R, Frost J 2003;Ellershaw J,Ward C 2003;Keay TJ, Alexander C 2003;Parker RG, Janjan NA 2003;Pinderhughes ST,Morrison RS 2003;Ripamonti C,Brunelli C 2003;Schapiro R,Byock I 2003;Tranmer JE, Heyland D 2003;Woodgate RL, Degner LF 2003;Buckley G,Smyth A 2004) {IDT 5.1; CCS6,11,13,13.1, 13.2, 14, 14.1, 14.2}

53. **Anorexia/cachexia:** (Bruera E, Carraro S 1986;Bruera E, Chadwick S 1986;Bruera E, Brenneis C 1988;Bruera E, Macmillan K 1990;Bruera E 1994;Vigano A, Watanabe S 1994;Von Roenn JH, Armstrong D 1994;Watanabe S,Bruera E 1994;Kotler DP,Grunfeld C 1995;Bozzetti F, Amadori D 1996;Watanabe S,Bruera E 1996;Bruera E 1998b;Kotler DP 1998;Wood L, Palmer M 1998;Amigo P, Mazuryk ME 2000;Bernard SA,Bruera E 2000;Bruera E,Sweeney C 2000;Kotler LA,Walsh BT 2000;Strasser F,Bruera ED 2002;Berenstein EG,Ortiz Z;Bruera E,Castro M 2003)

54. **Anxiety:** (Bruera E, Carraro S 1986;Butters E, Higginson I 1992;Butters E, Higginson I 1993;Maguire P, Faulkner A 1993;Ibbotson T, Maguire P 1994;Breitbart W, Bruera E 1995;Ginsburg ML, Quirt C 1995;Massie MJ,Payne DK 1999;Shuster JL, Jr., Breitbart W 1999;2000;Payne DK,Massie MJ 2000;Pasacreta J, Minarik P 2001;Breitbart W, Chochinov HM 2004)

55. **Delirium:** (Brenneis C, Michaud M 1987;Bruera E 1991;Stiefel F,Bruera E 1991;Stiefel F, Fainsinger R 1992;Harrison J,Maguire P 1994;Yue M, Fainsinger RL 1994;Breitbart W, Marotta R 1996;Boyle DM, Abernathy G 1998;Lawlor PG, Watanabe S 1998;Shuster JL, Jr., Breitbart W 1999;Breitbart W,Cohen K 2000;Lawlor PG, Fainsinger RL 2000;Lawlor PG, Gagnon B 2000;Lawlor PG, Nekolaichuk C 2000;Kuebler KK, English N 2001;Barnes EA, Palmer JL 2002;Breitbart W, Gibson C 2002;Breitbart W, Tremblay A 2002;Ingham J,Caraceni A 2002;Lawlor PG,Bruera ED 2002;Caraceni A,Grassi L 2003;Breitbart W, Chochinov HM 2004)

56. **Depression:** (Hardman A, Maguire P 1989;Hopwood P, Howell A 1991b;Hopwood P, Howell A 1991a;Depression Guideline Panel 1993;Block SD,Billings JA 1994;Fallowfield LJ, Hall A 1994;Ford S, Fallowfield L 1994;Ibbotson T, Maguire P 1994;Billings JA 1995;Breitbart W, Bruera E 1995;Vigano A, Watanabe S 1995;Chochinov HM, Wilson KG 1998;Ganzini L, Johnston WS 1998;Miller PJ, Hedlund SC 1998;Covinsky KE, Kahana E 1999;Massie MJ,Payne DK 1999;Shuster JL, Jr., Breitbart W 1999;Block SD,Panel for the American College of Physicians-American Society of Internal Medicine End-of-Life Care Consensus Panel 2000;U.S. Preventive Services Task Forces 2000;Wilson KG, Chochinov HM 2000;Block S. D. 2001;Breitbart W, Rosenfeld B 2001;Lloyd-Williams M,Friedman T 2001;Nelson JE, Meier DE 2001;Filiberti A,Ripamonti C 2002;Lloyd-Williams M 2002;National Institute of Health Consensus Development Program 2002;Nelson CJ, Rosenfeld BJ 2002;Breitbart W, Chochinov HM 2004)

57. **Dyspnea and other respiratory symptoms:** (Rueben DB,Mor V 1986;Ajemian I 1991;Bruera E, de Stoutz N 1993;Bruera E, MacEachern T 1993;Bruera E 1994;Addington-Hall J, Lay M 1995;Bennett MI 1996;Corner J, Plant H 1996;Kuebler KK, Dahlin C 1996;Adam J 1997;Boyd KJ,Kelly M 1997;Ripamonti C,Bruera E 1997;Rousseau P 1997;Ripamonti C, Fulfaro F 1998a;Zepetella G 1998;American Thoracic Society 1999;Bruera E, Belzile M 1999;Ripamonti C 1999;Schwartzstein RM 1999;Bruera E, Schmitz B 2000;Dudgeon DJ, Kristjanson L 2001;Barnes EA, Palmer JL 2002;Cohen SP,Dawson TC 2002;Coyne PJ, Viswanathan R 2002;Ripamonti C,Fusco F 2002;Shimoyama N,Shimoyama M 2002;Spector N,Klein D 2002;Agarwal R,Shaw P;Jennings AL, Davies AN 2003)

58. **Fatigue:** (Bruera E, Brenneis C 1988;Breitbart W, Bruera E 1995;Ferrell BR, Grant M 1996;Monti M, Castellani L 1996;Kaasa T, Loomis J 1997;Vogelzang NJ, Breitbart W 1997;Breitbart W, McDonald MV 1998;Cella D, Peterman A 1998;Barroso J 1999;Grant M, Golant M 2000;Krishnasamy M 2000;Liao S,Ferrell BA 2000;Mock V, Atkinson A 2000;Oyama H, Kaneda M 2000;Porock D, Kristjanson LJ 2000;Adinolfi A 2001a;Adinolfi A 2001b;Bormann J, Shively M 2001;Breitbart W, Rosenfeld B 2001;Cella D, Davis K 2001;Given CW, Given B 2001;Lee KA, Portillo CJ 2001;Miramontes H 2001;Barnes EA,Bruera E 2002;Barroso J,Lynn MR 2002;National Institute of Health Consensus Development Program 2002;Passik SD, Kirsh KL 2002)

59. **Gastrointestinal:** (Bruera ED, Roca E 1983;Bruera E, Jackson FI 1985;Brenneis C, Michaud M 1987;Bruera E, Brenneis C 1988;Bruera E 1994;Bozzetti F, Amadori D 1996;Baines MJ 1997;Oneschuk D,Bruera E 1997;Amigo P, Mazuryk ME 2000;Mercadante S, Ripamonti C 2000;Wenk R, Bertolino M 2000;Ripamonti C, Twycross R 2001;Choi YS,Billings JA 2002;Filiberti A,Ripamonti C 2002;Ahmed N, Ahmedzai S 2003;Feuer DJ,Broadley KE 2003;Goodman ML,Wilkinson S 2003;Westby MJ 2003)

60. **Genitourinary:** (Smith P,Bruera E 1995;Gray M,Campbell FG 2001;Norman RW,Bailly G 2004)

61. **Hiccups:** (Kolodzik PW,Eilers MA 1991;Ramirez FC, Graham, D.Y 1992;Bruera E, MacEachern T 1993;Okuda Y, Kitajima T, Asai T 1998;Walker P, Watanabe S 1998;Lewis JH 2000)

62. **Mucositis/stomatitis/xerostomia:** (De Conno F, Ripamonti C 1989;Rothwell BR,Spektor WS 1990;Guchelaar HJ, Vermes A 1997;Sweeney MP, Bagg J 1997;Bruera E 1998c;Sweeney MP, Bagg J 1998;Oneschuk D, Hanson J 2000c; Dahlin C, Goldsmith T 2001;Borbasi S, Cameron K 2002;Shih A, Miaskowski C 2002;Deane K, Whurr R 2003; Clarkson JE, Worthington HV 2003)

63. **Nutrition/hydration:** (Billings JA 1985;Bruera E, Brenneis C 1988;Bruera E, Brenneis C 1989;Yan E,Bruera E 1991;Bruera E 1994;Bozzetti F, Amadori D 1996;Bruera E, Belzile M 1996;Mitchell SL, Kiely DK 1997;Mitchell SL, Kiely DK 1998;Steiner N,Bruera E 1998;Covinsky KE, Martin GE 1999;Bruera E 2001;Gessert CE,Calkins DR 2001;Sarhill N, Walsh D 2001;Guggenheimer J,Moore PA 2003;Mitchell SL 2003)

64. **Skin care:** (Payne RL,Martin ML 1990;Camp-Sorrell D 1991;O'Rourke ME 1991;U.S. Agency for Health Care Policy and Research 1992;Payne RL,Martin ML 1993;Schulte MJ 1993;Femia C,Smith R 1994;Seaman S 1995;Tumberello J 1995;Ayello EA 1997;Haisfield-Wolfe ME,Rund C 1997;Baranoski S, Salzberg CA 1998;Ayello EA 1999;Ayello EA, Thomas DR 1999;Baranoski S 1999;Goebel RH,Goebel MR 1999;Haisfield-Wolfe ME,Baxendale-Cox LM 1999;Ayello EA 2000;Baranoski S 2000b;Baranoski S 2000a;Grocott P 2000;Hampton S 2000;Maffei A, Ayello J 2000;2000;Grocott P,Cowley S 2001;Trent JT,Kirsner RS 2001;Wilkes L, White K 2001;Ayello EA,Braden B 2002;Ayello EA, Cuddigan J 2002;Baldwin KM 2002;Belmin J, Meaume S 2002;Froiland KG 2002;Hess CT 2002;Holloway S, Bale S 2002;Yoshikawa TT 2002;Baranoski S,Thimsen K 2003;Bosonnet L 2003;Henoch I,Gustafsson M 2003;Odierna E,Zeleznik J 2003;Piggin C 2003;Trent JT,Kirsner RS 2003a;Trent JT,Kirsner RS 2003b)

65. **Sleep disturbance/insomnia:** (Gibson J,Grealish L 2001;Hirst A,Sloan R 2002)

III. ORGAN DYSFUNCTION

66. **Bone metastases:** (Oneschuk D,Bruera E 1996;Fulfaro F, Casuccio A 1998;Ripamonti C, Fulfaro F 1998b;Barton MB, Dawson R 2001;Ripamonti C,Fulfaro F 2001;Martinez MJ, Roque M 2003a;Martinez MJ, Roque M 2003b)

67. **Cardiac disease:** (Konstam M, Dracup K 1994;Burns RB, McCarthy EP 1997;Wolinsky FD, Overhage JM 1997;Wolinsky FD, Smith DM 1997;Krumholz HM, Phillips RS 1998;Maddocks I 1998;Goodlin SJ, Zhong Z 1999;Leland JY 2000;Levenson JW, McCarthy EP 2000;Anderson H, Card C 2001;Flowers B 2003;Mueller PS, Hook CC 2003;Nordgren L,Sorensen S 2003)

68. **Dementia:** (Ferrell BA 1995;McCarthy M, Addington-Hall J 1997;Teno JM, Landrum K 1997;O'Brien T, Welsh J 1998;Solomon MZ,Jennings B 1998;Finucane TE, Christmas C 1999;Lynn J, Teno J 1999;Volicer L 1999;Hurley AC, Volicer L 2000;Volicer L 2001;Volicer L, Hurley AC 2001;Evers MM, Purohit D 2002;Hurley AC,Volicer L 2002;Boult L, Dentler B 2003;Manfredi PL, Breuer B 2003;Volicer L, Hurley AC 2003)

69. **Endocrine/metabolic disorders:** (Markell MS,Friedman EA 1990;Kovacs CS, MacDonald SM 1995;Walker P, Watanabe S 1996;Walker P, Watanabe S 1997;Rajagopal A, Kala S 2003)

70. **Liver disease:** (Bolder U, Brune A 1999;Roth K, Lynn J 2000;Kimoto T, Yamanoi A 2001;Riley TR, 3rd,Bhatti AM 2001a;Riley TR, 3rd,Bhatti AM 2001b;Riley TR, 3rd, Chinchilli VM 2001;Donckier V, Van Laethem JL 2003;Testa R, Testa E 2003)

71. **Neurological disease:** (Borasio GD,Voltz R 1997;Smyth A, Riedl M 1997;Borasio GD,Voltz R 1998;Carter GT,Miller RG 1998;Ganzini L, Johnston WS 1998;Carver AC, Vickrey BG 1999;Ganzini L, Johnston WS 1999;Parker D, Maddocks I 1999;Oliver D, Borasio GD 2000;Ben-Zacharia AB,Lublin FD 2001;Borasio GD, Shaw PJ 2001;Foley KM,Carver AC 2001;Mandler RN, Anderson FA, Jr. 2001;Bradley WG 2002)

72. **Pulmonary conditions:** (Bruera E 1990;Gentile VG,Isaacson G 1996;von Gunten CF,Twaddle ML 1996;Hansen-Flaschen J 1997;Kesten S 1997;Lord E 1997;Robinson WM, Ravilly S 1997;Haddad A 1998;Tonelli MR 1998;Westwood AT 1998;Acres JC 2000;Claessens MT, Lynn J 2000;Hansen-Flaschen JH 2000;Heffner JE 2000;Hodson ME 2000;Levy MM 2000;Lynn J, Ely EW 2000;Mitchell I, Nakielna E 2000;Edmonds P, Karlsen S 2001;Ferrin M, Happ MB 2001;Hansen-Flaschen JH 2003)

73. **Renal disease:** (Neu S,Kjellstrand CM 1986;Campbell ML 1991;Cohen LM, McCue JD 1995;Henderson ML 1995;Hamel MB, Phillips RS 1997;Mesler DE, Byrne-Logan S 1999;Cohen LM, Germain MJ 2003;Poppel DM, Cohen LM 2003)

III. OTHER SYMPTOM CONTROL TOPICS

74. **HIV/AIDS:** (Expert Working Group on Integrated Palliative Care for Persons with AIDS 1988;Corless IB, Fulton R 1992;Butters E, Higginson I 1993;Goldstone I 1995;Grothe TM,Brody RV 1995;Kemp C,Stepp L 1995;McKeogh M 1995;Fantoni M, Ricci F 1997;O'Neill JF,Alexander CS 1997;Wood CG, Whittet S 1997;Ropka M,Williams A 1998;Meyer M 1999;Newshan G,Sherman DW 1999;Vogl D, Rosenfeld B 1999;Witteveen PO, Jacobs HM 1999;Corless IB,Nicholas PK 2000;Greenberg B, McCorkle R 2000;Nicholson J,Turner N 2000;O'Neill JF, Marconi K 2000;Maartens G, Bekker LG 2001;Matheny SC 2001;Coyne PJ, Lyne ME 2002;Karasz A, Dyche L 2003;O'Neill J,Marconi K 2003;O'Neill JF, Selwyn PA 2003;Selwyn PA,Forstein M 2003)

75. **Emergencies:** (Baines MJ 1997;Boyd KJ,Kelly M 1997;Falk S,Fallon M 1997;Gagnon B,Bruera E 1998;Gagnon B, Mancini I 1998;Abrahm JL 1999;Ripamonti C 1999;Mercadante S, Villari P 2002;Ripamonti C,Fusco F 2002;Jennings AL, Davies AN 2003;Saunders Y, Ross JR 2003)

76. **Trauma:** (Campbell ML,Frank RR 1997;American Academy of Pediatrics and the American College of Emergency Physicians 2002;Seward E, Greig E 2003)

77. **Care in the ICU:** (Shortell SM, Zimmerman JE 1994;Keenan SP, Busche KD 1997;Lynn J, Harrell F, Jr. 1997;Prendergast TJ,Luce JM 1997;Dowdy MD, Robertson C 1998;Glance LG, Osler T 1998;Keenan SP, Busche KD 1998;Danis M, Federman D 1999;Burns JP, Mitchell C 2000;Ostermann ME, Keenan SP 2000;Schneiderman LJ, Gilmer T 2000;Teno JM, Fisher E 2000;Burns JP, Mitchell C 2001;Curtis JR,Rubenfeld GD 2001;Puntillo KA, Benner P 2001;Rubenfeld GD, Randall Curtis J 2001;Baggs JG 2002;Catlin A,Carter B 2002;Campbell ML,Guzman JA 2003;Schneiderman LJ, Gilmer T 2003)

78. **Pharmacology issues:** (Bruera E, Roca E 1985;Ripamonti C,Bruera E 1991;Bernard SA,Bruera E 2000;Peuckmann V, Fisch M 2000;Choi YS,Billings JA 2002;Ripamonti C,Bianchi M 2002;Ripamonti C, Sweeney C 2002)

79. **Complementary medicine:** (Bruera E, Fainsinger R 1995;Finlay IG,Jones OL 1996;Bruera E 1998a;Jenkins CA, Scarfe A 1998;Oneschuk D, Fennell L 1998;Cassileth BR 1999;Decker GM 1999;Oneschuk D,Bruera E 1999;Abel J 2000;Daveson BA,Kennelly J 2000;Nield-Anderson L,Ameling A 2000;Oneschuk D, Hanson J 2000a;Paice JA, Ferrans CE 2000;Paice JA, Ferrons CE 2000;National Hospice and Palliative Care Organization 2001a;Demmer C,Sauer J 2002;Langenfeld MC, Cipani

E 2002;Zeltzer LK, Tsao JC 2002;Brenner ZR,Krenzer ME 2003;Garnett M 2003;Hilliard RE 2003;Buckle S 2003;Manfredi PL,Gonzales GR 2003;Sanders H, Davis MF 2003;Schofield P,Payne S 2003)

80. **Standardized instruments of assessment:** (Cohen SR, Mount BM 1996b;Neuenschwander H, Bruera E 1997;Teno JM, Byock I 1999;Donnelly S 2000;Teno J 2000;Anandarajah G,Hight E 2001;Novak B, Kolcaba K 2001;Teno JM, Casey VA 2001;Volicer L, Hurley AC 2001;Cohen SR,Leis A 2002;Passik SD, Kirsh KL 2002;Sulmasy DP 2002;Deeken JF, Taylor KL 2003;McClain CS, Rosenfeld B 2003)

Domain 3: Psychological and Psychiatric Aspects of Care

81. **Psychological distress in death and dying:** (Maguire P 1985;Devlen J, Maguire P 1987a;Devlen J, Maguire P 1987b;Miller RD,Walsh TD 1991;Dunn SM, Patterson PU 1993;Evans AJ 1994;Parle M, Jones B 1996;Davis CG, Nolen-Hoeksema S 1998;Doka KJ 1998;National Comprehensive Cancer Network 1999;Emanuel EJ, Fairclough DL 2000;Greenstein M,Breitbart W 2000;Powazki RD, Palcisco C 2000;Rando TA 2000;Steinhauser KE, Clipp EC 2000;Kornblith AB, Herndon JE 2001;Teno JM, Casey VA 2001;Yedidia MJ,MacGregor B 2001;Jansen LA,Sulmasy DP 2002a;Werth JL, Jr., Gordon JR 2002;Kissane DW, McKenzie M 2003;National Comprehensive Cancer Network 2003a;Pitceathly C,Maguire P 2003)

82. **Professionals with training and skills in providing appropriate care to diverse patient populations:** (Haines A,Booroff A 1986;Maguire P 1990;Caldwell J,Scott JP 1994;Chevrier F, Steuer R 1994;Maguire P, Booth K 1996;Maguire P, Faulkner A 1996;Scott JP,Caldwell J 1996;Parle M, Maguire P 1997;Seely JF, Scott JF 1997;Sherry KL, Bruera E 1997;Maguire P, Walsh S 1999;Lemkin P 2001;Payne S 2001;Leipzig RM, Hyer K 2002)

83. **Assessment of psychological reactions:** (Robbins RA 1991;Ginsburg ML, Quirt C 1995;Taube AW, Jenkins C 1997;Rousseau P 2000b;Block SD 2001;Roberts S, Black C 2002)

84. **Treatment of psychiatric symptoms and use of tools:** (Depression Guideline Panel 1993;Prigerson HG, Maciejewski PK 1995;Kissane DW, Bloch S 1997;Bernabei R, Gambassi G 1998;Lawlor PG, Watanabe S 1998;Lawlor PG, Nekolaichuk C 2000;Teno JM, Harrell FE, Jr. 2000;U.S. Preventive Services Task Forces 2000;Kuebler KK, English N 2001;Lloyd-Williams M 2001;Breitbart W, Gibson C 2002;National Institute of Health Consensus Development Program 2002;Brodaty H, Green A 2003;Caraceni A,Grassi L 2003;National Comprehensive Cancer Network 2003a) {NHPCO: IDT}

85. **Quality of life in end stage diseases, including measurement tools:** (Higginson I, Wade A 1990;Bruera E, Kuehn N 1991;Cohen SR,Mount BM 1992;Higginson IJ,McCarthy M 1994;Cohen SR, Mount BM 1995;Wu AW, Damiano AM 1995;Cohen SR, Mount BM 1996a;Cohen SR, Mount BM 1996b;Cohen SR, Bultz BD 1997;Cohen SR, Mount BM 1997;Greisinger AJ, Lorimor RJ 1997;Hearn J,Higginson IJ 1997;Lynn J 1997;Neuenschwander H, Bruera E 1997;Rudberg MA, Teno JM 1997;Chang VT, Thaler HT 1998;Donaldson MS,Field MJ 1998;Smeenk FW, van Haastregt JC 1998;Tierney RM, Horton SM 1998;Axelsson B,Sjoden PO 1999;Brady MJ, Peterman AH 1999;Singer P, Martin DK 1999;Singer PA, Martin DK 1999a;Singer PA, Martin DK 1999b;Stewart AL, Teno J 1999;Teno JM, Byock I 1999;Cohen SR,Mount BM 2000;Donnelly S 2000;Gabany JM 2000;Steinhauser KE, Christakis NA 2000;Steinhauser KE, Clipp EC 2000;Tolle SW, Tilden VP 2000;Cohen SR, Boston P 2001;DeSilva DL, Dillon JE 2001;Hickman SE, Tilden VP 2001;Sahlberg-Blom E, Ternestedt BM 2001;Chochinov HM, Hack T 2002a;Cohen SR,Leis A 2002;Contro N, Larson J 2002;Grant M,Hanson J 2002;Miller SC, Mor V 2002;Miller SC,Mor VN 2002;Steinhauser KE, Bosworth HB 2002;Steinhauser KE, Clipp EC 2002;Thompson G,McClement S 2002;Vig EK, Davenport NA 2002;Aspinal F, Addington-Hall J 2003;Llobera J, Esteva M 2003;Miller SC, Mor V 2003;Patrick DL, Curtis JR 2003;Scott JT, Harmsen M 2003;Tranmer JE, Heyland D 2003;Vig EK,Pearlman RA 2003)

86. **Assessment of patient coping and support**: (Maguire P, Hopwood P 1985;Vachon ML, Kristjanson L 1995;Chapman KJ,Pepler C 1998;Doka KJ 1998;Kavanaugh KM 1998;Roy DJ 1998;Russell P,Sander R 1998;Prigerson HG,Jacobs SC 2001;Yedidia MJ,MacGregor B 2001)

87. **Assessment of family coping and support**: (Sheehan CJ 1985;Bascom PB,Tolle SW 1995;Kelly B, Edwards P 1999;Bartel DA, Engler AJ 2000;Hockley J 2000;Thielemann P 2000;Andrews SC 2001;Wogrin C 2001;Main J 2002;Patterson LB,Dorfman LT 2002;Brazil K, Bedard M 2003;Brodaty H, Green A 2003;Dawson S,Kristjanson LJ 2003;Deeken JF, Taylor KL 2003;Kissane DW, McKenzie M 2003;Volicer L, Hurley AC 2003) See also caregiver burden (21)

88. **Grief and bereavement in various patient populations**: (Rando TA 1984;Kane RL, Klein SJ 1986;McIntyre BB 1990b;Couldrick A 1992;Levy LH, Derby JF 1993;Rando TA 1993;Payne S,Relf M 1994;Prigerson HG, Reynolds CF, 3rd 1994;Prigerson HG, Frank E 1995;Prigerson HG, Maciejewski PK 1995;Brown LF, Reynolds CF, 3rd 1996;Connor SR,McMaster JK 1996;Jacob SR 1996;Prigerson HG, Bierhals AJ 1996;Prigerson HG, Shear MK 1996;Rosenzweig AS, Pasternak RE 1996;Frank E, Prigerson HG 1997;Gillance H, Tucker A 1997;Hall M, Buysse DJ 1997;Kissane DW, McKenzie DP 1997;Pasternak RE, Prigerson H 1997;Prigerson HG, Bierhals AJ 1997;Prigerson HG, Shear MK 1997;Rozenzweig A, Prigerson H 1997;Szanto K, Prigerson H 1997;Brown-Saltzman K 1998;Corr CA,Corr DM 1998;Davis CG, Nolen-Hoeksema S 1998;Hall M, Baum A 1998;Schlernitzauer M, Bierhals AJ 1998;van Doorn C, Kasl SV 1998;Zygmont M, Prigerson HG 1998;Chen JH, Bierhals AJ 1999;Potts S, Farrell M 1999;Prigerson HG, Bridge J 1999;American Academy of Pediatrics Committee on Psychosocial Aspects of Child and Family Health 2000;Christ GH 2000;Cuthbertson SJ,

Margetts MA 2000;Prigerson HG, Maciejewski PK 2000;Rando TA 2000;Casarett D, Kutner JS 2001;Corless IB 2001;Payne S 2001;Prigerson HG,Jacobs SC 2001;Silverman GK, Johnson JG 2001;Barry LC, Kasl SV 2002;Barry LC,Prigerson HG 2002;Christ GH, Bonanno G 2002;Christ GH, Siegel K 2002;Kirk K,McManus M 2002;Pearce MJ, Chen J 2002;Prigerson HG 2002;Rawlings D,Glynn T 2002;Rynearson EK, Favell JL 2002;LeBrocq P, Charles A 2003;O'Connor M, Nikoletti S 2003;Kissane DW 2004)

89. **Grief and bereavement education for palliative care professionals**: (Rando TA 1984;Couldrick A 1992;Huart S,O'Donnell M 1993;Rando TA 1993;Corless IB, Germino B, Pittman M 1994;Brown CK 1995;Prigerson HG, Frank E 1995;Bouton BL 1996;American Academy of Pediatrics Committee on Psychosocial Aspects of Child and Family Health 2000;Barnes K 2001;Casarett D, Kutner JS 2001;Matsushima T, Akabayashi A 2002)

90. **Grief and bereavement education for families**: (Brown LF, Reynolds CF, 3rd 1996;Davis CG, Nolen-Hoeksema S 1998;Bartel DA, Engler AJ 2000;Casarett D, Kutner JS 2001;Ringdal GI, Jordhoy MS 2001;Ellison NM,Ptacek JT 2002;Kirk K,McManus M 2002;Prigerson HG 2002) {IDT 5.1,6.3,3.3}

91. **Bereavement support for children**: (McIntyre BB 1990a;McIntyre BB 1990b;Carroll ML,Griffin R 1997;Gillance H, Tucker A 1997;Cox G 1998;Davies B 1999;Potts S, Farrell M 1999;American Academy of Pediatrics Committee on Psychosocial Aspects of Child and Family Health 2000;Doka K 2000;Davies B 2001)

92. **Grief and bereavement risk assessment and reassessment**: (Payne S,Relf M 1994;Worden W 1996;Frank E, Prigerson HG 1997;Teno JM, Clarridge B 2001;Melliar-Smith C 2002) {BCS 2, 2.1, 2.2, 2.3, 3.4}

93. **Bereavement services**: (Bouton BL 1996;Hanson LC, Danis M 1997;Hoffman C 1997;Block SD 2001;Payne S 2001;Warren NA 2002;Schulz R, Mendelsohn AB 2003) {IDT 1.1; BCS 1}

94. **Staff support for those providing end-of-life care**: (Millison M,Dudley JR 1992;Higginson IJ,McCarthy M 1993;Harper B 1994;Vachon MS 1995;Davies B, Clarke D 1996;Maguire P, Booth K 1996;Vachon ML 1998;Barnes K 2001;Kristjanson LJ, McPhee I 2001;Leuthner SR,Pierucci R 2001;Puntillo KA, Benner P 2001;Yam BM, Rossiter JC 2001;Hanks GW, Robbins M 2002;Patterson LB,Dorfman LT 2002;Vachon MLS 2004) {BCS 4, 4.1, 4.1}

Domain 4: Social Aspects of Care

95. **Social assessment and care plan**: (Burrs FA 1995;Koenig BA,Gates-Williams J 1995;Davis A 1996;Eleazer GP, Hornung CA 1996;Hallenbeck J, Goldstein MK 1996;Koenig BA 1997;Morrison RS, Zayas LH 1998;Christ GH,Sormanti M 1999;Loudon RF, Anderson PM 1999;Emanuel EJ, Fairclough DL 2000;Hopp FP,Duffy SA 2000;Keovilay L, Rasbridge L 2000;Larson DG,Tobin DR 2000;Reese D, Raymer M 2000;Waters CM 2000;Curtis JR, Wenrich MD 2001;Contro N, Larson J 2002;Crawley LM, Marshall PA 2002;Wright EP, Kiely MA 2002;Seymour J 2003;Tong E, McGraw SA 2003) {IDT 1.1, 5.1, 11, 11.1-11.3; CCS 6, 6.1-6.3, 7, 7.1, 7.2, 9, 9.1-9.3, 10, 10.1-10.3, 11, 11.1, 11.3, 12, 12.1-12.2, 13, 13.1, 13.2, 14, 14.1, 14.2}

96. **Family structure and geographic location, relationships and intimacy, and communication in the family**: (Fins JJ,Solomon MZ 2001;Glajchen M,Zuckerman C 2001)

97. **Work and school**

98. **Finances**: (Covinsky KE, Goldman L 1994;Covinsky KE, Landefeld CS 1996;Emanuel EJ, Fairclough DL 2000)

99. **Sexuality**: (Chapman RM 1982;Rice A 2000;Rice AM 2000;Kaub-Wittemer D, Steinbuchel N 2003)

100. **Legal issues**: (Baluss ME 2002;Derse AR 2002)

101. **Routine patient and family meetings**: (Davis A 1996;Eleazer GP, Hornung CA 1996;Hallenbeck J, Goldstein MK 1996;Ambuel B 1999;Hallenbeck J,Goldstein MK 1999;Hopp FP,Duffy SA 2000;Larson DG,Tobin DR 2000;Curtis JR, Patrick DL 2001;Contro N, Larson J 2002;Scott JT, Harmsen M 2003)

Domain 5: Spiritual, Religious and Existential Aspects of Care

102. **Definitions: religious, spiritual, existential**: (Frankl V 1962;Cassell ES 1982;Grey A 1994;Kearney M,Mount BM 2000;Breitbart W 2002)

103. **Importance of spirituality for patients and families**: (Corless IB, Fulton R 1992;Oxman TE, Freeman DH, Jr. 1995;Taylor EJ, Amenta M 1995;Kark JD, Shemi G 1996;Kaldjian LC, Jekel JF 1998;Koenig HG, George LK 1998;Mytko JJ,Knight SJ 1999;Cox G 2000;Daaleman TP,VandeCreek L 2000;Rousseau P 2000c;Astrow AB, Puchalski CM 2001;Koenig HG 2001;Koenig HG, Larson DB 2001;Mueller PS, Plevak DJ 2001;Fife RB 2002;Koenig HG 2002;Nelson CJ, Rosenfeld BJ 2002;Steensma DP 2002;Mount BM 2003;Sheehan MN 2003;Taylor EJ 2003;Cassidy JP,Davies DJ 2004)

104. **Assessment of spiritual/religious/existential needs of patient and family, and related professional skills training:** (Taylor EJ, Amenta M 1995;Maugans TA 1996;Puchalski CM,Larson DB 1998;Baider L, Russak SM 1999;Cassell EJ 1999;Holland JC, Passik S 1999;Lo B, Quill T 1999;Sloan RP, Bagiella E 1999;Sulmasy DP 1999;Highfield ME 2000;Post SG, Puchalski CM 2000;Puchalski CM,Romer AL 2000;Sloan RP, Bagiella E 2000;Anandarajah G,Hight E 2001;Astrow AB, Puchalski CM 2001;Hermann CP 2001;Kornblith AB, Herndon JE 2001;Lo B, Ruston D 2002;Nelson CJ, Rosenfeld BJ 2002;Puchalski CM 2002;Sloan RP,Bagiella E 2002;Sulmasy DP 2002;McClain CS, Rosenfeld B 2003) {IDT 7, 7.1, 11, 11.2}.

105. **Responding to spirituality: interventions and their outcomes**: (Levin JS, Larson DB 1997:Sumner CH 1998:Block SD 2001: Hebert RS, Jenckes MW 2001:Sulmasy DP 2001:Roberts L, Ahmed I 2003)

106. **Cultural sensitivity to religious preferences**: (Crawley L, Payne R 2000;Highfield ME 2000;Sherman AC,Simonton S 2001;Kagawa-Singer M 1998;Kagawa-Singer M 2001;Krakauer EL, Crenner C 2002;Moadel A, Morgan C 1999) {IDT 7.1}

107. **Sensitive use by institutions of religious symbols, while patients/families display their own symbols and follow their own rituals**: (Neuberger J 1994;Kagawa-Singer M 1998a)

108. **Access to clergy**: (Goldberg R, Guadagnoli E 1990;Cassidy JP,Davies DJ 2004)

109. **Family guidance on wake, memorial service, burial, cremation**: (Weber M, Ochsmann R 1998;Bern-Klug M, Ekerdt DJ 1999;Morgan E 2001;Ellison NM,Ptacek JT 2002;Gatrad R,Sheikh A 2002) {CC 2.6}

Domain 6: Cultural Aspects of Care

110. **Issues of access to end-of-life care within culture and community**: (Gates MF 1991;Todd KH, Samaroo N 1993;Todd KH, Lee T 1994;Phillips RS, Hamel MB 1996;Meier DE, Morrison RS 1997;Chochinov HM,Kristjanson L 1998;Culture Project on Death in America and the Center on Crime and Culture 1999;Haber D 1999;Petrisek AC,Mor V 1999;Reese DJ, Ahern RE 1999;Crawley L, Payne R 2000;Zerzan J, Stearns S 2000;Metzger M,Kaplan KO 2001;Crawley LM, Marshall PA 2002;Dixon S, Fortner J 2002;Flaskerud JH, Lesser J 2002;Gatrad R,Sheikh A 2002;2002;Last Acts 2002;Payne R,Payne TR 2002;Payne SK, Coyne P 2002;Schneider EC, Zaslavsky AM 2002;Allen RS, DeLaine SR 2003;Maddocks I,Rayner RG 2003;Soares LG 2003)

111. **Cultural Assessment**: (Pickett M 1993;Blackhall LJ, Murphy ST 1995;Hallenbeck J, Goldstein MK 1996;Murphy ST, Palmer JM 1996;Bates MS, Rankin-Hill L 1997;Voltz R, Akabayashi A 1997;Bernabei R, Gambassi G 1998;Sagara M,Pickett M 1998;Beutter MB,Davidhizar R 1999;Blackhall LJ, Frank G 1999;Carrillo JE, Green AR 1999;Cykert S, Joines JD 1999;Borum ML, Lynn J 2000;Karim K, Bailey M 2000;Zoucha R 2000;Zoucha R,Husted GL 2000;Christopher M,Emmott H 2001;Gessert CE,Calkins DR 2001;Sahlberg-Blom E, Ternestedt BM 2001;Thomas ND 2001;Vincent JL 2001;Baggs JG 2002;Crawley LM 2002;Crawley LM, Marshall PA 2002;Kobylarz FA, Heath JM 2002) {CCS 6.1; 11.1, 11.2, 12.4; IDT 4.1.9, 5.1, 7.3}

112. **Cultural identification**: (Koenig BA,Gates-Williams J 1995;Noggle BJ 1995;Bates MS, Rankin-Hill L 1997;Brenner PR 1997;Koenig BA 1997;Kagawa-Singer M 1998a;Kagawa-Singer M 1998b;Morrison RS, Zayas LH 1998;Baggs JG 1999;Oncology Nursing Society 1999;Reese DJ, Ahern RE 1999;Taylor A,Box M 1999;Waters CM 2000;Byock I, Norris K 2001;Kagawa-Singer M,Blackhall LJ 2001;McCracken LM, Matthews AK 2001;Berger A, Pereira D 2002;Crawley LM, Marshall PA 2002;Iwashyna TJ,Chang VW 2002) {IDT 4, 4.1.9, 5, 5.1.10, -7, 7.1.3}

113. **Communication within various cultures**: (Koenig BA,Gates-Williams J 1995;Connors RB, Jr.,Smith ML 1996;Davis A 1996;Hakim RB, Teno JM 1996;Hallenbeck J, Goldstein MK 1996;Koenig BA 1997;Ersek M, Kagawa-Singer M 1998;Hamel R 1998;Hallenbeck J,Goldstein MK 1999;Moadel A, Morgan C 1999;Dowsett SM, Saul JL 2000;Hopp FP,Duffy SA 2000;Waters CM 2000;Bowman KW,Singer PA 2001;Christopher M,Emmott H 2001;Kagawa-Singer M,Blackhall LJ 2001;Levy MM 2001;Thompson G,McClement S 2002)

114. **Education on cultural diversity**: (Brant J, Ishida D 2000;Ekblad S, Marttila A 2000;Christopher M,Emmott H 2001;Krakauer EL, Crenner C 2002)

115. **Cultural rituals**: (Kagawa-Singer M 1998a;Kagawa-Singer M 1998b;Romanoff BD,Terenzio M 1998;Langford JM 2000;Kagawa-Singer M,Blackhall LJ 2001;Mariano C 2001;Miles SH 2001;Mitty EL 2001) {ARE 2, 2.1, 2.2}

116. **Translation**: (Langford JM 2000;Soloman NRZ 2000;Kagawa-Singer M,Blackhall LJ 2001;Sullivan MC 2001)

117. **Recruitment for diversity**: (Haber D 1999;Karim K, Bailey M 2000;Mechanic D 2002) {HR 8, 8.1, 8.2}

Domain 7: Care of the Imminently Dying Patient

118. **The imminently dying phase is recognized, documented, and communicated**: (Ventafridda V, Ripamonti C 1990;Pickett M,Yancey D 1998;The AM, Hak T 2000;Ellershaw J, Smith C 2001;Kristjanson LJ 2001;Ellershaw J,Ward C 2003;Furst CJ,Doyle D 2004)

119. **End-of-life concerns, hopes and expectations are addressed openly and honestly**: (Neuenschwander H, Bruera E 1997;Lo B, Quill T 1999;Carrese JA, Mullaney JL 2002) {CCS 9, 9.3, 12}

120. **End-of-life concerns are addressed in the context of social and cultural customs**: (Pickett M 1993: National Hospice and Palliative Care Organization 1996;Coyle N, Ingham JM 1999) {CCS 12.3}

121. **End-of-life concerns are addressed in a developmentally appropriate manner**: (Lo B, Quill T 1999;Wolfe J, Grier HE 2000;Wolfe J, Klar N 2000;Perrin KO 2001;Rauch P,Arnold R 2002;Rauch PK, Muriel AC 2002) {CCS 9, 9.3, 12}

122. **Symptoms assessed and treated**: (Hastings Center 1987;Lichter I,Hunt E 1990;Ventafridda V, Ripamonti C 1990;Fainsinger R, Miller MJ 1991;Truog RD, Berde CB 1992;Cherny NI,Portenoy RK 1994;Brody H, Campbell ML 1997;Pickett M,Yancey D 1998;Coyle N, Ingham JM 1999;Du Pen SL, Du Pen AR 1999;Wolfe J, Grier HE 2000;Rousseau P 2002) {See Domains 2 and 3} {CCS 2, 3}

Domain 8: Ethical and Legal Aspects of Care

123. **Interdisciplinary team includes professionals knowledgeable in ethics**: (Council on Ethical and Judicial Affairs AMA 1992;Rushton CH, Hogue EE 1993;Glover JJ,Rushton CH 1995;Quill TE,Cassel CK 1995;Payne K, Taylor RM 1996;Quill TE,Brody H 1996;Bruera E, Selmser P 1997;Post LF,Dubler NN 1997;Scanlon C 1997;Bruera E, Fornells H 1998;Quill TE, Meier DE 1998;Scanlon C 1998;Singer PA,MacDonald N 1998;Council on Ethical and Judicial Affairs AMA 1999;Ziring PR, Brazdziunas D 1999;Csikai EL,Bass K 2000;Meisel A, Snyder L 2000;Zoucha R,Husted GL 2000;Beauchamp TL,Childress JF 2001;Casarett D, Ferrell B 2001;Forde R, Aasland OG 2001;Price KJ,Kish SK 2001;Bascom PB,Tolle SW 2002;Jansen LA,Sulmasy DP 2002a;Kyba FC 2002;O'Keefe ME,Crawford K 2002;Brett AS,Jersild P 2003;Lee S,Kristjanson L 2003;Olthuis G,Dekkers W 2003;Quill TE,Cassel CK 2003)

124. **Assessing decision-making capacity**: (Miles SH, Koepp R 1996;Koenig BA 1997;Hopp FP 2000;Mezey M, Teresi J 2000;Norton SA,Talerico KA 2000;Ganzini L, Volicer L 2003;Volicer L,Ganzini L 2003)

125. **Surrogate decision making**: (Baggs JG 1993;Baggs JG,Schmitt MH 1995;Baggs JG,Schmitt MH 1997;Baggs JG, Schmitt MH 1997;Brody H, Campbell ML 1997;Dowdy MD, Robertson C 1998;Goodlin SJ, Winzelberg GS 1998;Pritchard RS, Fisher ES 1998;Baggs JG, Schmitt MH 1999;Braddock CH, 3rd., Edwards KA 1999;Baggs JG,Mick DJ 2000;Meisel A, Snyder L 2000;Silveira MJ, DiPiero A 2000;Steinhauser KE, Christakis NA 2000;Steinhauser KE, Clipp EC 2000;Teno JM, Fisher E 2000;Zoucha R,Husted GL 2000;Chochinov HM 2002;Chochinov HM, Hack T 2002a;Chochinov HM, Hack T 2002b;Doukas DJ,Hardwig J 2003;Ryndes T,Emanuel L 2003) {ARE 3, 3.5;IDT 11}

126. **Ethical issues in palliative care**: (Blackhall LJ, Murphy ST 1995;Glover JJ,Rushton CH 1995;American College of Physicians--American Society of Internal Medicine End-of-Life Care Consensus Panel 1998;Dowdy MD, Robertson C 1998;Scanlon C 1998;Scanlon C,Rushton CH 1998;Mezey M, Teresi J 2000;Schwartz JK 2001;Stanley KJ,Zoloth-Dorfman L 2001;Boult L, Dentler B 2003;Cantor MD, Braddock CH 2003;Calman K, MacDonald N 2004) {ARE 8, 8.1, 8.2}

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1 References from sections of the National Hospice and Palliative Care Organization Standards of Practice for Hospice Programs (2002) are cited in brackets, using their abbreviations as follows:

ARE	Access, Rights, Ethics	MI	Management of Information
BCS	Bereavement Care and Services	PI	Performance Improvement and Outcomes Measurement
CC	Coordination and Continuity of Care	SIC	Safety and Infection Control
CCS	Clinical Care and Services	HIF	Hospice Inpatient Facility
HR	Human Resources	NF	Nursing Facility Hospice Care
IDT	Interdisciplinary Team	HRCF	Hospice Residential Care Facility
LG	Leadership and Governance		

Appendix 1

Palliative Care and the Hospice Movement in the United States

While new clinical specialties in palliative medicine and nursing are emerging, palliative care has been delivered through hospice programs in the United States for over 30 years. Hospice care is paid for by Medicare and other insurers through a regulated benefit influencing both access to hospice and the types of services that hospices are able to provide. Under current Medicare/Medicaid guidelines, hospice care is covered for beneficiaries of these programs who are certified by their physician as likely to die within six months if the disease follows its usual course, and who are willing to give up insurance coverage for medical treatments of the terminal illness that are focused on cure or on prolongation of life. Many private payers have similar hospice benefits, although these benefits often have day or dollar caps without requirement that coverage of other services be waived. Once the hospice benefit has been accessed, patients and families may receive comprehensive services across all settings of care from an interdisciplinary team, although the great majority of hospice care is delivered at home. Medicare/Medicaid and most commercial insurances pay for medications and equipment related to the terminal illness, as well as practical, psychosocial, respite and bereavement support for caregivers. (1, 4)

As a prelude to understanding the palliative care movement in the United States, it is helpful to recall the context in which the Medicare hospice benefit was enacted in the early 1980s. Post-World War II scientific advances in health care and medical education created an almost exclusive focus on organ systems, disease states and injury-related models of care. Due to technological advances and major public health initiatives during this era, life expectancy grew considerably, and cure became an expectation. The age-old concern for the patient's suffering and the quality of his or her life, a staple of medical practice and the ethos of medicine throughout history, seemed eclipsed by the focus on medical technology. Dying became a medical event, usually in a hospital, and often accompanied by significant pain and isolation.

The hospice movement represented a countercultural phenomenon. In effect, hospice advocates urged the government to give Medicare patients an alternative approach to high-technology, hospital-based medicine, and elect, instead, to pursue a course of palliative care. In retrospect, this forced choice of either curative care or palliative care seems short-sighted. The assumptions that patients with terminal prognoses could be successfully and easily identified and that they, in turn, would wish to use hospice care, were not borne out. Furthermore, advances in costly, and variously effective, interventions that could concurrently ameliorate symptoms, improve quality of life, and potentially increase life expectancy were not foreseen, making the six-month rule and fixed per diem hospice reimbursements appear increasingly arbitrary. (1, 3, 4)

Notwithstanding these insights, the hospices that grew out of the movement of the late 1970s and early 1980s have been successful. Surveys in the United States have consistently demonstrated a high rate of satisfaction with hospice services. (22) The goals of hospice programs are to create increased opportunity for death at home, to focus on the symptom-control and psychological and spiritual issues that are paramount for persons in the terminal phases of an illness, and to provide bereavement support for their families. Since 1974, over 7 million patients and their families have received end-of-life care at home (e.g., a private residence, assisted living facility, group home, homeless shelter) as well as in nursing homes and hospitals through hospice programs, with escalating use in recent years. (1)

The treatment philosophy and primary clinical characteristics of hospice care and palliative care are shared. (5) Both palliative care and hospice programs:

- Acknowledge the patient and their family as the unit of care, and value reduction of caregiver mortality and morbidity by actively reducing the physical and emotional burden associated with caregiving and grief.
- Rely on interdisciplinary assessment, treatment and evaluation.
- Energetically respond to the consequences of illness facing the patient and family, including:
  - Managing symptoms.
  - Providing practical guidance and support of care at home, where most people spend most of their time and most prefer to be as death approaches.
  - Offering anticipatory counseling/crisis prevention/critical decision support.
  - Recognizing the need for health promotion, even in the face of physical decline.
- Address common forms of patient abandonment, such as health care workers' dismissal of patients who "failed therapy," believing "nothing more can be done."
- Incorporate a human development perspective with respect to life-altering illness.

Responding to Community Need

Since the mid-1980s, leading hospices have aimed to expand access to services in order to reach people based on human need, if these individuals did not meet Medicare hospice eligibility requirements or state hospice licensure definitions. Some hospices have contributed to palliative care education through relationships with local universities and colleges in schools of medicine, nursing, pastoral care and social work. Hospice programs that provide services beyond conventional hospice benefits are referred to as "upstream hospice," while those with dedicated professional education, research and public policy/advocacy components are referred to as "comprehensive hospice centers." Some programs have used the term "open access to hospice" to describe their program's absence of proscription on taking all terminally ill patients under care. (3)

In the past eight to ten years, physicians, nurses and other health care professionals in universities and teaching institutions have championed palliative care efforts to improve care for those seriously ill patients who do not meet hospice eligibility criteria or choose not to elect hospice care. These services, while variably defined,

have been collectively termed "palliative care services." They may be independent of hospice services or contractually related to hospices.

Hospices working "upstream" have encountered both financial and regulatory obstacles in their efforts to offer comprehensive services to patients who either do not meet Medicare or other eligibility guidelines or who may benefit from costly therapies that greatly exceed the per diem payment of the Medicare Hospice Benefit. The Medicare requirements governing hospices inhibit treatment of patients with prognoses longer than six months; as a result, hospices have established alternative programs and relationships in order to respond to the palliative care needs of patients who are ineligible for hospice. The continuing debate over whether and how to extend the reach of hospice care (either through the expansion of their duties or the lengthening of the qualifying terminal prognosis) has made it obvious that there is a broader issue than hospice care to be considered.

Hospice care is completely appropriate at the end of life, but palliative care, in one form or another, is indicated, throughout all phases of life, whenever there are significant burdens from illness or trauma. Expanding the reach of hospice care, therefore, is not the answer to the broader need for palliative care. The values that underlie palliative care—namely holistic outlooks, case management and attention to the patient's quality of life and personhood—are values that must be integrated into the health care system of which hospice is already an effective part. (1-4)

Hospice Utilization and Growth

Significant increases both in number of programs and in number of patients served by hospice programs have been documented in recent years. (1) More than 885,000 patients and their families received hospice care in 2002, an increase of nearly 15 percent over the previous year.

Approximately 80 percent of patients who die in the United States experience a variable period of illness and functional decline before death during which they would benefit from palliative care. It is estimated that hospices provide care to 40 percent of adult Americans who experience death with a preceding period of dependency in activities of daily living, and in 2002, 50 percent of U.S. hospice patients had noncancer diagnoses. Currently, more than half of American adult patients who die with a diagnosis of cancer opt for hospice, while in some communities over 90 percent of patients with cancer receive hospice care before death. An additional 2 million caregivers received family/bereavement services from hospice programs in 2002. (1) Due both to regulatory and insurance restrictions to access, and because of the exceptional difficulty of accepting death as a normal process in this patient population, a smaller proportion of pediatric deaths (about 10 percent) are served by hospice. Pediatric hospice programs have grown, especially among larger hospices, in recent years in response to community need. (3)

Bereavement services are a regulatory requirement of certified hospice programs. A recent matched cohort study, employing Medicare claims data of 195,553 elderly spouses of hospice and nonhospice decedents, demonstrated improvement in survival rates for the spouses of hospice decedents, particularly among wives.

The palliative care needs of patients and families across the continuum should be met by a genuine partnership between palliative care and traditional hospice programs. Close coordination and partnerships between palliative care and hospice programs is critical to the support of genuine continuity of palliative care throughout the course of illness and across the continuum of care settings. Palliative care programs will grow to address the needs of patients and families with long and indeterminate life expectancies. Late in the disease course, the complex and intensive terminal care needs of most patients and families facing the end of life are often best met by comprehensive hospice care.

As of 2002, 41 percent of hospices are delivering palliative care services outside the Medicare Hospice Benefit, and another 19 percent are planning such services in order to increase access to palliative care to patients who are ineligible for or unwilling to enter hospice programs. (1) Nearly a third of the nation's 3,200 hospices are hospital-based, and many hospital, nursing home and home-care agency palliative care programs have been both initiated and supported by hospice professionals. Data suggest that palliative care programs in a range of care settings (24) result in marked increases in the number of appropriate and timely referrals to hospice.

As a philosophy of care, the palliative care services and care management offered by hospices should be available to any patient and family who can benefit from them. Access to hospice programs should not be influenced by the availability of life-prolonging therapies or the patient's desire to pursue these approaches, since many, if not most, patients wish to continue life-prolonging treatments as long as the treatment benefits outweigh the burdens. Since these goals are not mutually exclusive, rational policy would support efforts to amend the Medicare/Medicaid "waiver of other services" requirements, and require instead continual reevaluation of cost-beneficial therapies and payment structures.

Finally, while this document has largely focused on the development of guidelines that have a high degree of applicability in institutional settings, additional focused efforts are needed to improve access to hospice and palliative care for Americans in nursing homes, where limited resources, regulatory obstacles and staff turnover often limit the availability of expert interdisciplinary palliative care services. (29-30) Interdisciplinary teams in nursing homes, in partnership with hospitals, hospices and other community resources, must continue to acquire the training and credentialing in palliative care necessary to care for this patient population. The availability of contracts with community hospices is another important, feasible and growing approach to improving access to palliative care services in the nursing home setting.

Palliative Care Services

There is reason to be optimistic about improving access to palliative care services. As of 2002, more than 25 percent of academic medical centers and well over 950 hospitals (about 20 percent of all hospitals in the U.S.) indicate that they provide access to a palliative care program, including hospice. Additionally, nearly a third of the 3,200 U.S. hospices are hospital-based. In the last seven years, more than 1,200 physicians (including 18 pediatricians) have been certified as subspecialists by the American Board of Hospice and Palliative Medicine *(www.abhpm.org)* and approximately 7,000 registered nurses, 43 advanced practice nurses, and nearly 1,000 nursing assistants are certified in palliative care *(www.nbchpn.org)*. Over the last three years, more than 1,000 physicians and 1,500 nurses have attended three-day-long educational conferences sponsored by Education for Physicians in End-of-Life Care *(www.epec.net)* and the adult and pediatric End-of-Life Nursing Education Consortium *(www.aacn.nche.edu/elnec/)*. There are 42 postgraduate medical fellowship programs and two graduate nursing programs in palliative care across the country, and more are in planning stages *(www.aahpm.org)*. In 2003, over 2,300 clinicians attended the NHPCO-HPNA Joint Clinical Conference to advance their skills in hospice and palliative care and more than 1,500 health professionals, representing over 600 hospitals and hospices, attended conferences sponsored by the Center to Advance Palliative Care which were aimed at helping health professionals and managers start and sustain palliative care programs *(www.capc.org)*. Improvements in access to pediatric palliative care have evolved through demonstration models *(www.chionline.org)*, development of pediatric palliative care curricular materials *(www.ippcweb.org and www.nhpco.org)*, as well as increases in federal funding for both pediatric and adult palliative care research. Several programs targeted to nursing home professionals have also been developed *(www.capc.org/specialpopulations)*. (30) Educational initiatives in social work include several fellowship training programs and Web-based curricula *(www.swlda.org)* and *(www2.soros.org/death/swlda)*. (28)

History of the National Consensus Project

Development of U.S. palliative care consensus guidelines was discussed during a national leadership conference coordinated by the Center to Advance Palliative Care *(www.capc.org)* that was held in December 2001 at the New York Academy of Medicine. Participants at this conference (listed at *www.nationalconsensusproject.org*) were identified through a national peer nomination process. The early goals of the National Consensus Project were:

1. To define an effective national consensus process for establishment of clinical practice guidelines for quality palliative care in the United States.

2. To develop such guidelines through an evidence-based iterative review process that involved the major palliative care organizations in the United States and a large number of professionals in diverse disciplines.

3. To disseminate these guidelines to all stakeholders involved in the delivery of health care to persons with life-threatening illnesses in the United States.

A time line detailing the activities of the National Consensus Project between December 2001 and the publication of these guidelines may be found at w*ww.nationalconsensusproject.org.*

Organizational Structure of the National Consensus Project

The National Consensus Project has been structured to maximize the participation and input of a broad range of palliative care professionals, health care organizations, policy and standard-setting bodies, consumers and payers. To this end, a series of working groups has been formed to ensure a comprehensive, transparent and representative consensus process underpinning the development of Clinical Practice Guidelines for Palliative Care.

Consortium Organizations for the NCP: Based on recommendations from the broader palliative care community, five key national palliative care organizations formed a consortium to oversee and ensure the success of the National Consensus Project. The consortium includes:

- **American Academy of Hospice and Palliative Medicine:** A physician membership organization for palliative care and hospice professionals. (*www.aahpm.org*)
- **Center to Advance Palliative Care:** A Robert Wood Johnson Foundation–funded initiative to promote the development of quality palliative care programs in hospitals and other health care settings. (*www.capc.org*)
- **Hospice and Palliative Nurses Association:** A nursing membership organization for palliative care and hospice professionals. (*www.hpna.org*)
- **Last Acts Partnership:** A national, not-for-profit organization dedicated to improving care and caring near the end of life by informing health care professionals, advocating for policy change, and empowering private citizens with information and opportunities for action. (*www.lastactspartnership.org*)
- **National Hospice and Palliative Care Organization:** A hospice and palliative care advocacy and provider membership organization serving U.S. hospices, palliative care members and their professional staffs. (*www.nhpco.org*)

Steering Committee: Each of the five consortium organizations has appointed four representatives to a Steering Committee (members are listed on page vi). The Steering Committee was charged with the writing and timely completion of the consensus document, communication and dissemination of progress reports to all appropriate NCP participants, and procurement of the necessary financial support for the project. The committee made all decisions regarding the NCP through a voting process at its regular monthly meetings.

Advisory Committee: An Advisory Committee (members are listed in Appendix 2) was established concurrently with the Steering Committee. This group, which includes 96 nationally recognized palliative care leaders nominated by their peers, served as document reviewers and key contributors to document development and revision.

Liaison Organizations: During the process of document creation, a list of liaison organizations was developed. More than 100 organizations with major responsibility for the health care of patients with life-threatening illnesses in the U.S. were asked to offer their endorsement and to assist in the broadest possible national dissemination of the standards.

Process for Developing Consensus

The Steering Committee developed a process for drafting and reviewing the document. The steps in this process are as follows:

- The Steering Committee developed an outline that identified the key domains after review of all existing standards and consensus documents (31) and input from the Advisory Committee.
- Clinical practice guidelines were developed based on consensus and the best available scientific evidence.
- Drafts of the document were reviewed and edited by the Steering Committee. Using a 1–4 scale, the committee reviewed and rated each section/item. A score of 1 was a full rejection; 2 was a rejection with multiple reservations; 3 indicated acceptance with reservations; and 4 indicated full acceptance of the section/item.
- The Steering Committee reviewed and discussed the tally of the ratings and comments, and through discussion resolved or revised any item receiving less than 70 percent agreement.
- The revised document was reviewed by the Steering Committee. When more than 70 percent of committee members voted to accept the document, it was distributed to the Advisory Committee for review and rating using the 1-4 scale, and to the five consortium organizations for review by their boards of directors or respective governing bodies.
- Feedback and ratings by the Advisory Committee and consortium organizations were tallied and reviewed by the Steering Committee. Subsequent revisions were reviewed, voted on and approved by the Steering Committee. Unanimity of approval by the boards of all five consortium organizations was required at this stage of document development.
- The document was then distributed to all the liaison organizations for endorsement and assistance in national dissemination of the guidelines.
- In order to ensure the success and effectiveness of the project in improving access to quality palliative care in the United States, a comprehensive communication and dissemination plan for the document was developed. The plan is intended to ensure distribution of the guidelines to organizations, associations, clinicians, managers, providers, policy-makers, educators, researchers and other individuals who plan, provide or assess palliative care programs.

Appendix 2

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